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Adherence with Childhood Cancer Treatment in Kenya

Festus Muigai Njuguna

ADHERENCE WITH CHILDHOOD CANCER TREATMENT IN KENYA

Festus Muigai Njuguna

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VRIJE UNIVERSITEIT

ADHERENCE WITH CHILDHOOD CANCER TREATMENT IN KENYA

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de Vrije Universiteit Amsterdam,

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CHAPTER 1

INTRODUCTION

1.1 Global Perspective on Childhood Cancer

1.1.1 Prevalence and Incidence

Cancer has increasingly been noted by the World Health Organization (WHO) as one of the leading causes of morbidity and mortality globally. Worldwide there were about 14 million cases of cancer with about 8.2 million deaths. The number of new cases is expected to increase by over 70% over the next two decades to reach 22 million. (1)

Childhood cancer is rare and comprises 1% of all cancers. (2)Globally there are about 180,000 cases of childhood cancer worldwide with 80% of them occurring in low and middle-income countries.(3-5) Childhood cancer incidence is about 130 cases per million children under the age of 15 years in high-income countries. (6) However, the incidence rates have been reported to be lower in low and middle-income countries with an average of 102 cases per million children under the age of 15 years. Within the various low and middle-income countries the incidence rates vary markedly though, with for instance 64 cases per million in India, 45 per million in South Africa, and 29 per million in Namibia.(2,4-6)

The differences in incidence of childhood cancer between high versus low and middle- income countries may to a very limited extent be due to differences in environmental exposures and other biologic variables. However, major deficiencies in diagnosis and registration contribute very significantly to these observed differences in the incidence between high versus low and middle-income countries.(6,7)

In low and middle-income countries serious barriers exist before a child can be diagnosed with cancer and registered.(figure 1.) Once the symptoms develop, the families first need to seek care at a primary level health facility. The parents should have a way of paying for the costs of transport as well overcome the allure of the alternative medicine to be able to get to this facility. The health worker should be able to suspect cancer based on the signs and symptoms the child presents with. Lack of knowledge among the health-care workers provides a barrier to the ultimate diagnosis. If the health-care worker at the primary care facility suspects cancer the child is then referred to the next level of care and ultimately to the centers that are able to provide

care for children with cancer. This may involve going through several levels of hospitals which wastes time and increases the costs for the families. Once they get to the cancer care centers appropriate diagnostic equipment are required to confirm the diagnosis and properly stage the patient. Lack of these facilities and sometimes lack of funds to pay for the various tests may cause impediments to the process. Qualified personnel are also key in making this final diagnosis and there is a huge gap of trained and experienced personnel in many low and middle-income countries. After a diagnosis is ultimately made the last step will usually be to have the child registered into a database. Data entry clerks are required as well as equipment like computers or paper to store the data. If the institutions have no data entry clerks or lack the equipment, this further compromises the registration system.(4,8)

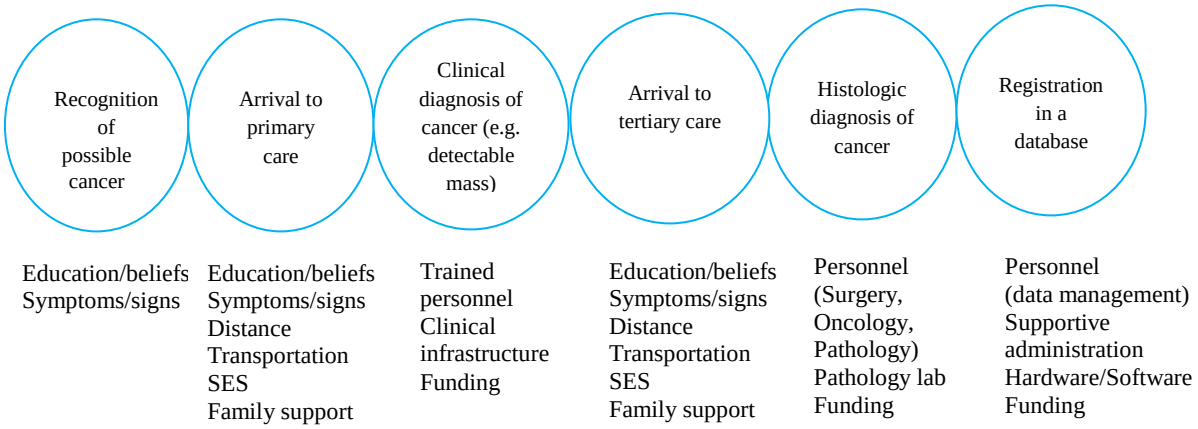

Figure 1. Links in the Chain of Childhood Cancer Diagnosis and Registration with Potential Barriers in Low and Middle-Income Countries
Source: Gelband H et al (4)

1.1.2 Types of Childhood Cancers

Childhood cancer is a rare disease that can evolve in various systems or organs. The types of childhood cancers are classified depending on their cell of origin. Two main types can be distinguished: hematological malignancies and solid cancers.

Hematological malignancies are types of childhood cancer that develop in blood forming tissue as the bone marrow, and in cells of the immune system. Hematological malignancies can be divided in two categories: leukemias and lymphomas. The leukemias are malignancies that usually arise from the hemopoietic cells from the bone marrow and are grouped depending on their cell of origin into myeloid or lymphoid leukemias. They are also further sub-classified into acute or chronic

leukemias depending on whether the malignant cells are immature or not. Lymphomas arise from the reticu-endothelial system and are divided into two groups: Hodgkin lymphoma and non-Hodgkin lymphoma. This distinction is made upon examination of the abnormal cells identified in the sample from a biopsy or aspiration of the tumor tissue. In Hodgkin lymphoma Reed-Sternberg cells are present.(9)

Solid cancers contain a group of malignant cells with the capacity to invade ambient tissue and to metastasize. Solid cancers can arise from any other body tissue and they are classified and named depending on the organ or tissue of origin, for instance medulloblastoma from the brain, Wilms tumor from the kidney, and osteogenic sarcoma from the bone. (9)

In high-income countries acute lymphoblastic leukemia is the most common childhood cancer, followed by brain tumors and then lymphomas. In low and middle-income countries brain tumors are more rarely diagnosed. This may be related to the lack of neuro-imaging facilities necessary for diagnosis and the limited possibilities to conduct tumor biopsies. (6)

Although in most low and middle-income countries acute lymphoblastic leukemia is also the most common hematological tumor, the situation is different for Sub-Saharan Africa. In Sub-Saharan countries non-Hodgkin lymphoma is the most commonly diagnosed pediatric malignancy, followed by acute lymphoblastic leukemia. This increased incidence of non-Hodgkin lymphoma is related to the malaria endemicity in many parts of this region. The development of Burkitts lymphoma, which is one subtype of non-Hodgkin lymphoma, is associated with chronic malaria infection. (6)

1.1.3 Treatment

Treatment of childhood cancer involves three main modalities of treatment. These are chemotherapy, surgery and radiotherapy. Chemotherapy involves the use of drugs which are administered through various routes (oral, parenteral, intrathecal) which kill the malignant cells. Surgery basically involves resection of the tumors and is useful for the solid cancers. Radiotherapy involves use of radioactive energy to kill tumor cells and is generally used together with the other two modalities. Other newer modalities include use of monoclonal antibodies and other targeted therapies. Supportive care of childhood cancer patients is also very crucial. Some of the components of the

supportive care include: counseling, prevention and treatment of infections, pain management, nutritional support, prevention and treatment of tumor lysis syndrome. (10,11)

The treatment of childhood cancer requires a multidisciplinary team that includes pediatric oncologists or pediatricians, radio-oncologists, surgeons, nurses, pharmacists, social workers, nutritionists, child life specialists amongst other team members.(10)

In most of the low and middle-income countries there is a shortage of qualified personnel to perform the roles outlined as compared to the high-income countries. Lack of proper and adequate equipment also affects delivery of care to the patients. Other challenges to the delivery of care to the patients in low resource settings include late presentation, treatment abandonment and presence of comorbidities.(4,12)

Some of the suggested solutions to the challenges encountered in low and middle-income countries include: establishment of twinning programs, use of adapted treatment regimens and the erection of training centers within low and middle-income countries.(4)

1.1.4 Survival

In high-income countries childhood cancer is the leading cause of non-accidental deaths after infancy. In low and middle-income countries childhood cancer mortality contributes only a very small portion of the overall childhood mortality. The mortality in these settings is mostly contributed by infectious causes. (4) However, there has been a shift over the last few years as regards the causes of mortality in children. In the year 2010 infections accounted for about 64% of all childhood deaths in low and middle-income countries but this has recently tremendously reduced in the middle-income countries. The latter have seen a proportional rise in the deaths caused by cancer.(4,8)

The survival of childhood cancer is around 80% in high-income countries. Low and middle-income countries, especially those in Africa, report survival rates of less than 35%. The mortality in low and middle-income countries contributes to more than 80% of the global childhood cancer mortality. (13-15)

Several factors contribute to these huge differences in survival between high versus low and middle-income countries. The human resource is underdeveloped in most of the low and middle-income

countries. They do not have qualified pediatric oncologists, pediatric surgeons, radio-oncologists as well as other members of the multidisciplinary team that is required to ensure proper care is delivered to pediatric oncology patients.(12)

The low and middle-income countries also lack the necessary infrastructure. Many countries in Africa lack radiotherapy capability which affects the outcomes of the patients who require it for cure. Blood transfusion facilities are understaffed and lack the capacity to have enough blood products which are very necessary for treatment of cancer. (6,12)

High poverty levels coupled with poor knowledge on childhood cancer lead to patients presenting with late stage disease. These patients subsequently usually have a poor prognosis. Lack of supportive care facilities leads to more treatment related deaths as well.(6,8,12)

Above all these factors, the leading cause of the huge disparities in childhood cancer survival is treatment abandonment. This problem has been noted in all regions of the world but is worse in low and middle-income countries where in some set ups up to 60% of patients abandon therapy. (6,8)

1.2 Childhood Cancer Treatment Adherence

The low survival of childhood cancer patients in low and middle-income countries has been attributed to a variety of factors. This includes inadequate childhood cancer diagnostic and treatment facilities as well difficulties in accessibility. Lack of trained personnel who should work in a multidisciplinary team also contributes. Late presentation which often necessitates more intense treatment increases the risk of treatment related mortality. Most of the patients also have a lot of comorbidities, including malnutrition, which increase rates of toxicity as well as death. Despite all the challenges however, the leading cause of poor treatment outcomes in low and middle-income countries is non-adherence and abandonment of childhood cancer treatment.(8)

1.2.1 Definitions

Various definitions of treatment adherence are in place. Treatment adherence can, for instance, be defined as “the degree or extent of conformity to the recommendations about day-to-day treatment by the provider” and as “the extent to which a patient acts in accordance with the prescribed interval, and dose of a dosing regimen”.(9) These

definitions describe a more paternalistic relationship between the health-care provider and patient. Another more accurate and realistic definition is “acting in accordance with the rules of the prescribed treatment schedules”. Adherence failure according to the latter definition is not restricted to patients and parents, but concerns doctors and other health-care providers too.(10)

Non-adherence has a wide spectrum and varies from a sporadic lapse to total abandonment of treatment. The International Society of Paediatric Oncology Abandonment of Treatment Working Group defined treatment abandonment as failure to start or continue the scheduled curative treatment during 4 or more consecutive weeks.(11)

1.2.2 Determinants

Adherence to treatment is importantly determined by the interplay of many factors at the patient and family level, as well as at the health-care providers’ level. In addition, characteristics of the disease and required treatment determine how well a treatment regimen is adhered to.

1.2.2.1 Patient

The age of patients is an important determinant of treatment adherence. Cancer treatment disturbs normal psychosocial development during childhood, leading to resistance and control struggles at different ages.(16-19)

Toddlers for instance may have difficulties with taking oral medications and may spit the medicines instead of swallowing them. Parents may ultimately get tired and omit the medicines. Furthermore young children may experience anxiety of separation during hospitalization. (16-19)

Adolescents have been found to be the least adherent with cancer treatment. This non-adherence may contribute to the inferior treatment outcomes of certain types of cancer, such as childhood leukemia, during adolescence. Normally the stage of adolescence represents a transition from childhood to adulthood. During this period adolescents undergo a lot of biological as well as psychosocial changes. The adolescents try to achieve self-identity, autonomy and independence. Some of them can become rebellious in the process. This rebellion and subsequent disagreement with parents stimulates the gain of emotional independence by adolescents. Having an illness like cancer disrupts this normal psychosocial development. Adolescents with cancer

become very dependent on other people. In addition, chemotherapy offered as part of cancer treatment affects their physical outlook since it causes for instance alopecia and affects their skin. This affects the self-esteem as they cannot participate in the same activities as their peers. Adolescents may therefore feel that it is better not to adhere to cancer therapy and try to be like other "normal" peers instead. During this period it can then become very difficult to know who is in charge of ensuring that medications and appointments are adhered to between the parents and the child. (16-19)

1.2.2.2 Family

The family plays a very crucial component in every patients' life especially when they have a chronic condition. This is particularly important for childhood cancer since it is a devastating illness that takes a long time and cost during the treatment.(17) The ability of families to adapt and cope with the news of a critical illness amongst one of their own is very crucial in promoting adherence. Families with good interpersonal relationships promote adherence, by offering affection and support to the family member who is affected by disease. Words of hope, optimistic attitudes and encouragement facilitates coping with the disease. Such families are able to communicate better and can remind the sick member about the need to take medication and keep their appointment with the health-care providers. For instance, adherence has been found to improve when parents accompany their children during hospital visits and stays at the clinic. On the contrary, a family that is unable to cope with the illness may demotivate the patient and make them loose hope and thereby be less adherent. Families thus have the potential to provide a very important social support system for patients. Patients with poor social support systems have less adherence.(14,16,19,)

Patients who are from families with poor socio-economic status are less adherent than those from richer backgrounds. Poverty which is more predominant in low and middle-income countries affects many factors that directly impact adherence. These would include the ability to pay for transport to keep appointments which has been shown in a number of studies to affect compliance. Poverty also makes families unable to pay for medical expenses including medications and investigations. This is especially a big problem in many low and middle-income countries where most families have no access to health insurance.(19-22)

Low education status of parents has a negative impact on adherence. It hinders seeking of medical help and can lead to poor understanding of the disease and necessity to adhere and complete treatment. This can especially be a huge barrier in countries like Kenya, where the doctors use a language (English) other than the local dialects which the patient and family may understand better. In addition, families with low education level are unlikely to read and learn more about the condition on their own initiative which further hinders their knowledge required to cope with the disease of their child.(18,22)

With enhanced knowledge and comprehension of the disease by parents and patients, cancer treatment adherence increases. When families have a realistic idea of the disease, its causes, the purpose of treatment, the need to comply, and the prognosis, adherence ameliorates. Detailed knowledge of medication administration is crucial: the substance, quantity, frequency, and side-effects need to be explained. Families misunderstanding the provided information and instructions of doctors more often fail to comply. (18,22)

The size of the family has been demonstrated to affect adherence as well. Large families with high number of siblings are less compliant. This may be because large families have more complex interpersonal dynamics and also the responsibilities of parents are increased. This may result in less time and energy for the child with cancer. In most low and middle-income countries the family size is larger than in high-income countries. (23, 24)

The beliefs and attitudes of families regarding the illness that the patient is suffering from affects adherence. If for instance families think that childhood cancer is incurable they will be less adherent to conventional medicine. If families believe that cancer is caused by witchcraft or a family curse they will probably seek alternative therapies for the child. This also has a ripple effect as the patient will usually then present with late disease that will have poor prognosis and requires more intense therapy which reduces adherence.(20,23)

An important reason for non-adherence is human error. This concerns forgetting to take medicines or attend hospital, a hectic lifestyle, bemusement, insufficient medication supplies at home, and no structured planning or supervision of drugs administration. (16)

1.2.2.3 Health-Care Provider

The health-care providers also significantly determine how well the prescribed treatment is adhered to. The beliefs of the health-care workers on the curability of childhood cancer will influence their interaction with the patient. Those who believe that cancer is incurable are unlikely to adhere to the treatment protocol themselves and thereby reduce the adherence of the patients and families.(17,21)

Communication is an important element as far as adherence is concerned. Doctors usually are trained in a technical language which most patients and families may not understand. Doctors and other health-care providers therefore need to simplify their language to be able to communicate with patients. Poor communication leads to poor adherence. The information provided by the health-care providers should cover the diagnosis, etiology, treatment to be offered and expected outcomes. It has been shown that giving clear information in a written format improves adherence. Further it is important that the communication is given on a continuous basis, from the time the suspicion of a malignancy is made upto the time the treatment and follow-up is being done. This improves adherence as opposed to a one time discussion.(18,21,23)

Having one consistent doctor to a patient improves adherence as opposed to a situation where the doctors change frequently. This may be related to the fact that the patients develop more trust in the doctor and are likely to follow on their instructions. The patient and the doctor also get to understand each other better and are able to communicate more effectively. The patient would feel more at ease and ask questions whenever they need any clarification.(18)

The attitudes and professional conduct of health-care providers affects the adherence of parents and patients. For instance, the doctors' willingness to provide time, attention and information directly affects the understanding of the family about curability of cancer and the effectiveness of the treatment being offered. When patients or parents understand better the need for using the medication and coming for appointment the more likely they are to adhere. In many low and middle-income countries doctors receive full time government salaries to attend public hospitals, yet work during office hours in private practices. This adversely affects how well parental education is given in public hospitals, and how timely protocols can be adhered to and patients taken care of. Studies reported that patients in private

hospitals adhere better with cancer treatment due to the enhanced and individualized attention patients and parents receive in these settings. Other studies illustrated that patients' adherence increases when patients and parents regard their doctor as friendly and feel respected by the doctor. If families are unsatisfied with the services that they are receiving they are less likely to be compliant.(16,21,23,25)

1.2.2.4 Disease

Adherence to treatment is also determined by disease related factors, such as the severity of the illness, absence of symptoms, stage of disease at diagnosis, morbidity and type of malignancy.

The simple presumption that when a disease is life threatening, treatment adherence ameliorates is false. A life threatening or severe disease does not automatically increase adherence.(14,24)

The absence of symptoms of disease can deteriorate adherence. When symptoms of a disease have cleared, for instance after achieving remission in childhood leukemia, parents and patients can easily forget to take prescribed medications or deny that there is still a problem. Poor treatment adherence can then be expected. Since there is no direct improvement in quality of life when they take the medication they may feel that it is of no value. Also failure to take medications does not lead to a worsening of symptoms immediately. This reduces adherence as the patient cannot associate their wellbeing with the medication.(14,24)

The stage of disease at diagnosis affects adherence. When patients present with advanced stages of cancer, as often is the case in low and middle-income countries, their prognosis decreases. The poorer prognosis and associated higher treatment costs can discourage both medical staff and parents to adhere with treatment. Late stage of disease usually requires more intensive treatment in order to achieve cure. The intense treatment causes more adverse effects which can lead to poor adherence.(22,24)

Morbidity is higher in children with cancer in low and middle-income countries, where malnutrition and infectious diseases are more prevalent. Consequently children in these settings are more vulnerable and less tolerant of chemotherapy. Higher morbidity can hereby reduce the ability to adhere to the required treatment schedules. (22,24)

Most studies conclude that the type of malignancy is not directly related to adherence. Although one might expect that patients with conditions requiring less intensive therapy find it more easy to adhere to the milder treatment schedules since its toxicity is less, this presumption is not correct. For instance in a study done in Sudan on Wilms tumor, a type of cancer requiring a relatively less intensive treatment, nearly 90% of the children abandoned treatment. Another study conducted in El Salvador found no difference in abandonment rates between various types of malignancies such as leukemias, lymphomas, central nervous system tumors and other solid tumors. (17,26,27)

1.2.2.5 Treatment

There are also several treatment related factors that affect adherence. These include the characteristics of the medication used. Factors like the taste, color and appearance of the medication affect adherence. Unpleasant tastes and unappealing colors and packaging of the medication would worsen adherence. Big size of tablets as well as liquid preparations of medications reduce adherence.(14,16)

The complexity of the medication regimen is very key in ensuring adherence. Having fewer medications that are administered few times in a day increases adherence. Patients who require multiple drugs are more adherent when they use fixed dose combination of drugs rather than taking each different drug on its own.(14,16)

Patients' adherence with cancer treatment tends to be better on inpatient versus outpatient care. Self-administration of medications leads to poor adherence compared to when the health-care providers administer them. (23)

The accessibility and availability of the medications is an important factor affecting adherence. This is especially important in low and middle-income countries where drugs are usually missing especially in public hospitals. Once patients miss drugs in the hospital they are unlikely to go back to the institution for refills. Unavailability of drugs is a product of corruption within the health-care systems in these countries.(23)

Duration and phase of treatment impacts adherence too. The longer the duration of treatment the poorer the adherence. This has especially been noted in patients receiving treatment for acute lymphoblastic leukemia which takes two years. There is better compliance in the early

part of the maintenance phase of treatment compared to the last weeks of treatment. It is however also important to note that it has been observed in some studies that adherence can reduce in the induction phase of acute lymphoblastic leukemia treatment which is the initial phase. This however can be attributed to other factors including the fact that the patients usually become more sick during induction and families then may lose hope easily.(14,24)

The perceived effectiveness of the treatment being offered has an impact on adherence. When the patient feels better soon after taking the medication they are likely to continue being adherent as opposed to treatment that does not make them feel better. Studies have showed reduced adherence during the maintenance phase of acute lymphoblastic leukemia treatment, partially caused by the fact that when doses of drugs are missed the symptoms do not return instantly.(14)

The frequency and severity of side effects is very key in improving adherence. Patients are more likely to be compliant if the treatment they are getting is not making them more sick as a result of the adverse effects.(22)

High costs of treatment diminishes adherence. Cancer treatment is expensive and involves payments for hospitalization, medicines, transportation to the hospital, loss of daily wages during hospital visits or stays. In low and middle-income countries most families attending public hospitals are already financially deprived. Financial debts can force these families to opt out of the potential curative cancer treatment. (17-19)

1.3 Kenya

1.3.1 Geography, Population and Economy

Kenya is a country situated on the Eastern part of Africa. It borders the Indian Ocean and Somalia to the East, Ethiopia and Southern-Sudan to the North, Uganda to the West and Tanzania to the South. It is part of the East Africa Community which is an economic bloc composed of 7 East African countries (18). The country has a total land area of 591,971 square kilometers and a population of about 45 million people. Kenya has a very young population with 42% being less than 15 years old. The country is classified as a lower middle-income country after being upgraded from the year 2015. The Gross Domestic Product per

capita is USD 1200. Almost half of the population (46%) lives below the poverty line. (28,29)

1.3.2 Health-Care Sector

The country spends 4.5% of the Gross Domestic Product on health. The health indicators have been improving over the past few years and the life expectancy is now 61 years. The infant mortality rate is 39/1000 while the under 5 mortality rate is 52/1000.(30,31)

Health-care in Kenya is provided by three different types of facilities: the public, private-for-profit and private-not-for-profit facilities. These facilities are organized into six different levels. Level one represents the community, where community health workers play a big role. Level two is composed of dispensaries which provide mainly health promotion and prevention services like vaccination and ante-natal services and basic curative services. They are staffed by nurses and public health technicians. At level three, the health centers are staffed by nurses, clinical officers and sometimes doctors. They provide basic curative and preventive services. The level four facilities are the district hospitals. These facilities provide 24 hour inpatient and outpatient services. They have laboratory and radiological diagnostic capabilities and they offer general surgical services. Level five facilities are the provincial hospitals. They provide specialized care whose skill and competence are not found in level four hospitals. Level six facilities are the tertiary national referral hospitals, which are supposed to be able to handle the complex curative services. They also serve as training facilities for both basic and postgraduate levels. (32)

Three main sources of financing the health-care system can be distinguished in Kenya. The out of pocket payments constitutes about 30%, with donor funding and the government revenue taking care of most of the rest. Both public and private facilities charge user fees. The private health facilities are generally used by the more wealthier people. Donor funding provides budgetary support for specific programs such as Human Immunodeficiency Virus care. The contribution of donor funding to the overall health expenditure grew from 16% in the year 2001-2002 to 35% in the year 2009-2010. (32)

1.3.3 Health-Insurance

About 10% of the Kenyan population has health-insurance, with the government owned National Hospital Insurance Fund (NHIF) and many small private insurance schemes providing this service. The NHIF in

general provides inpatient cover although in recent years they have started covering outpatient services as well. Contribution to NHIF is mandatory to all those who are in formal employment. The monthly contribution depends on the level of pay for the individual. Contributions to the scheme are also open to those in the informal sector who constitute the majority of the Kenyan working population. The monthly contribution by this group had been about 1.2 Euro, though this has been increased recently to about 4.5 Euro to cater for the outpatient cover. These amounts provide cover for the contributor and their nuclear family.(32,33)

1.4 Aims and Outline of Thesis

This study on adherence with childhood cancer treatment has been conducted at the Moi Teaching and Referral Hospital (MTRH). MTRH is a tertiary public hospital that is situated in Eldoret which is a town in North-Western Kenya. Eldoret is around 300 kilometers from Nairobi, the capital city of Kenya. It is a town with a population of about 300,000 residents.

MTRH serves as a referral hospital for the whole of Western-Kenya which has a population of about 18 million. The hospital has a bed capacity of 800 and provides specialized curative services in diverse areas. The pediatric oncology services include both outpatient as well as inpatient care. The hospital receives about 120 new pediatric oncology patients every year, although we would expect at least 700 patients given the catchment population.

The hospital has offered pediatric oncology services since the late 1990s. In the year 2009 the Department of Pediatric Oncology of MTRH started a collaboration with the Department of Pediatric Oncology-Hematology of the VU University Medical Center in Amsterdam, the Netherlands. This collaboration focuses on exchange of knowledge and skills between the two partners. It is facilitated by the KLM (Royal Dutch Airlines) through the Doctor2Doctor Program which provides air tickets and other logistical support.

The aims of this study are:

i) To investigate the epidemiology of childhood cancer at MTRH;
ii) To explore treatment outcomes and survival of childhood cancer at MTRH;
iii) To assess the magnitude and the factors which contribute to childhood cancer treatment abandonment in Kenya; and

iv) To investigate the barriers to accessing health care for childhood cancers in Kenya

The **second chapter** describes the epidemiology of childhood cancer seen at MTRH. Basic epidemiological information on childhood cancer in Western Kenya was lacking. This deficit obstructed efforts to improve the care and survival rates of children in this part of the world. The study was a retrospective chart review of all children 18 years or less diagnosed with cancer at MTRH between January 2006 and January 2009. We collected the names of 436 children from 3 different databases within the hospital and retrieved their medical records. The new comprehensive cancer registration can be used as the basis for an evidence-based oncology program.

The **third chapter** describes the magnitude of abandonment as well as the reasons that lead to abandonment among the childhood cancer patients in Western Kenya. This was done through home visits to the families that abandoned childhood cancer treatment at MTRH from January 2007 to January 2009.We obtained the parents contact information from the medical records and an independent interviewer visited 46 families to administer a semi-structured questionnaire. The questionnaire was focused on the reasons for abandonment as well as the condition of the child after treatment abandonment. The families living conditions were also assessed.

Chapter four explores whether childhood cancer treatment outcomes in Kenya are influenced by health insurance status and hospital detention practices. The study combined both a retrospective chart review and a case report. We included all children newly diagnosed with cancer at MTRH between January 2007 and January 2009, with treatment outcome documented in the medical records, and who were 0 and 19 years at diagnosis. We collected socio-demographic data and information about the diagnosis and outcomes from the medical records of 180 children. One child with acute lymphoblastic leukemia without health insurance at diagnosis was identified. The family was interviewed in their home in December 2011 using a semi-structured questionnaire.

Chapter five explores unique factors that were noted to lead to treatment abandonment in Western Kenya: parents' social network and experiences with hospital detention practices. This was an exploratory descriptive study. An independent interviewer visited homes of 46

patients who had abandoned treatment between the years 2007-2009 and interviewed their parents. A semi-structured questionnaire was used to assess how the parents' social network (parents, family, church, community) reacted to the information about the child's illness and how this affected their treatment decisions. We also explored their experiences with hospital detention practices and the hospital waiving procedures.

Chapter six looks into the experiences that parents have as their children undergo treatment at the hospital. This provides useful insights into the day to day issues they face which may contribute to the success or failure of the treatment. We interviewed all parents whose children came for treatment in MTRH from November 2012 to April 2013. A semi-structured questionnaire which focused on socio-economic, treatment related and psychological experiences was used. A total of 75 parents were interviewed.

Chapter seven looks at the health-care providers' perspectives towards childhood cancer. It provides useful insights on how different cadres of health care workers think about what causes childhood cancer, its treatment and outcome. This study was done through a self-administered questionnaire among all staff of the division of pediatrics at MTRH.The questionnaire covered health-care providers' health beliefs and attitudes towards parental financial difficulties, protocol adherence, parental education and communication. In total 104 health-care providers participated.

Chapter eight is a Personal View of the problem of corruption and how it affects health-care systems in Africa with specific reference to childhood cancer. It reviews the causes and the actors in the corruption network as well as suggesting the solutions to the issue. This was a review article on existing literature published from the low-income countries. Our research team was invited by the editorial board of The Lancet Oncology to write this Personal View.

Chapter nine focuses on assessing the factors that influence the time it takes for children with cancer to get into contact with the health-care system, be diagnosed and started on treatment. The study assessed the various types of delay (patient delay, health-care system delay, diagnosis delay, treatment delay, physician delay, total delay) among pediatric oncology patients seen at MTRH and to determine the factors that influence the time to diagnosis and start of treatment. We enrolled

newly diagnosed pediatric oncology patients from August 2013 to July 2014. A total of 99 participants were recruited and we used an interviewer administered semi-structured questionnaire. In addition, the medical record charts were evaluated to collect demographic and medical data.

Chapter ten provides insights into the outcomes and the factors influencing the outcomes of patients with Wilms tumor in this set-up. This study illustrates how all the issues discussed in the previous chapters affect the diagnosis, treatment and outcome of a specific malignancy in Kenya. The study was a retrospective medical records review that included all39 patients who were diagnosed with Wilms' tumor at the hospital between January 2010 and December 2012.

Chapter eleven defines the problem of hospital detention practices as well as suggests ways in which the problem can be tackled. As a position statement it is written by a special Global Taskforce on behalf of the International Society of Paediatric Oncology.

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CHAPTER 2

EPIDEMIOLOGY OF DIAGNOSED CHILDHOOD CANCER IN WESTERN KENYA*

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ABSTRACT

***Setting**: Basic epidemiologic information on childhood cancer in Western Kenya is lacking. This deficit obstructs efforts to improve the care and cure for children in this part of the world.*

***Objective:** Our study provides an overview of childhood cancer patients presenting for treatment in Western Kenya.*

***Design:** A retrospective analysis of childhood cancer patients presenting for treatment in Western Kenya was carried out using information from three separate databases at the Moi Teaching and Referral Hospital in Eldoret. All patients between 0-19 years first presenting between January 2006 and January 2010 with a newly diagnosed malignancy were included.*

***Results:** A total of 436 children with cancer were registered during the period. There were 256 (59%) boys and 180 (41%) girls with a male/female ratio of 1.4:1. The group aged 6-10 years contained most children (29%). Median age at admission was 8 years. Non-Hodgkin lymphoma was the most common type of cancer (34%), followed by acute lymphoblastic leukaemia (15%), Hodgkin lymphoma (8%), nephroblastoma (8%), rhabdomyosarcoma (7%), retinoblastoma (5%) and Kaposi sarcoma (5%). Only four (1%) children with brain tumours were documented. Ewing sarcoma was not diagnosed.*

***Conclusions:** Our study provides an overview of childhood cancer patients presenting for treatment in Western Kenya. The distribution of malignancies is similar to findings in other equatorial African countries but differs markedly from studies in high-income countries. The new comprehensive cancer registration will be continued and extended to establish an evidence-based oncology program. Eventually this may lead to improved clinical outcomes.*

***Abbreviation:** MTRH - Moi Teaching and ReferralHospital*

INTRODUCTION

In Western Kenya, the lack of basic epidemiological information on childhood cancers hampers understanding of the spectrum of childhood malignancies and the problems faced. This important pitfall must be addresses so that the care and survival rates of children in this part of the world can be improved.

At least 70% of childhood cancers are currently curable and about 80% of children with adequate cancer treatment are expected to survive. However only 20% of children affected worldwide benefit from the best available therapy. The vast majority of childhood cancer patients live in low income countries like Kenya and have only limited access to effective therapy and thus little or no chance of survival.(1-7)

This study aims to provide an overview of childhood cancer patients presenting for treatment to Moi Teaching and Referral Hospital (MTRH) the only hospital in Western Kenya treating children with cancer. MTRH did not have a comprehensive hospital based cancer registry of childhood cancer patients.

METHODS

Setting

Kenya is a low-income country and 50% of the population live below the poverty line. In2009 Kenya had 39 million inhabitants, 42%(16 million) of whom were children under under 15 years of age. The male/female sex-ratio was 1.01:1.00.(8)Kenya has only two academic hospitals able to provide oncology patients with treatment. The first is situated in the capital city Nairobi, while the second MTRH, is in Eldoret.

The study was carried out at MTRH the only hospital in Western Kenya treating children with cancer. MTRH serves an estimated population of 16-18 million people, 40-45% of all inhabitants of Kenya, including around 7 million children under 15 years of age. With a childhood cancer incidence in low income countries of 102 per million children under 15 years of age(9-11) we would expect around 700 childhood cancer patients under 15 years of age in the area served by MTRH.

MTRH has a total of 550 inpatient beds. The paediatric department has 72 of these beds, 12 of which are reserved for oncology patients, who are cared for by one or two paediatricians. The pathology services employ four pathologists who only use morphology (fine needle

aspirate or tissue biopsy) for diagnosis. Children are hospitalised during diagnosis. Children under 15 years of age are treated by a paediatrician in the paediatric ward, while children between 15 and 19 years of age are consulted by a paediatrician in an adult ward. Treatment options include surgery and chemotherapy, but radiotherapy is not available. Treatment protocols developed in the academic hospital in Nairobi are used. Starting in 2007, an outpatient clinic is held once a week with clinicians and nurses in attendance for patients who return home the same day. Paediatric and adult patients are seen together.

Study Design

All patients between 0-19 years with a newly diagnosed malignancy were included in the retrospective study. First presentation of patients occurred between January 2006 and January 2010.

No comprehensive hospital-based registry of childhood cancer patients was available at MTRH: although basic patient information had been collected in three separate databases, the databases had not been merged together. Patients were enrolled if their name was mentioned in at least one of the three databases: (1) the paediatric database, which was started by paediatricians in 2006 and consists of handwritten and electronic reports of hospitalised childhood cancer patients up to 19 years of age; (2) the computerised pathology database, into which pathologists have entered the results of biopsies ,fine needle aspirates, bone marrow aspirates and cerebrospinal fluid samples since 2004; and (3) the outpatient oncology database, which contains information on paediatric oncology patients attending day clinics since 2007. A new comprehensive cancer registration database was established by merging these three data sets together.

We collected the following variables: name and registration number of the childhood cancer patient, type of cancer, gender, age at admission and year of first admission. We determined which children were recorded in more than one database by matching names and registration numbers.

Malignancies were diagnosed by clinical observation and by histological examination which was often carried out on tumour material obtained by fi ne needle aspiration with May-Grünwald Giemsa (MGG) staining. Pathologists sent written diagnostic reports to the paediatrician, who inserted them in the medical records.

Malignancies were classified into six groups: (1) haematological tumours (acute lymphoblastic leukaemia, acute myeloid leukaemia, chronic myeloid leukaemia, non-Hodgkin's lymphoma, Hodgkin's lymphoma, anaplastic large cell lymphoma);(2) brain tumours (medulloblastoma, ependymoma, astrocytoma, glioma); (3) solid tumours (neuroblastoma, nephroblastoma, rhabdomyosarcoma, Ewing's sarcoma, osteosarcoma,

retinoblastoma, Kaposi's sarcoma); (4) rare tumours; (5) a group of 'unspecified' malignancies which included patients for whom only the primary site of the malignancy was known; and (6) an 'unconfirmed' group which consisted of patients mentioned in one of the three databases but for whom we could not confirm the diagnosis.

Data Analysis

Data management was performed with Microsoft Excel 2000.Descriptive statistics were used.

RESULTS

By using three different databases we gathered information of 436 childhood cancer patients who were first presented at MTRH between January 2006 and January 2010 and met the study's inclusion criteria. The paediatric database provided information on 354 (81%) patients, the pathology database on 157 (36%) patients and the outpatient oncology database on 78 (18%) children. Figure 1 illustrates that 40 (9%) children were registered in all three databases, 73 (17%) children in two databases and of 323 (74%) children information was noted in one database.

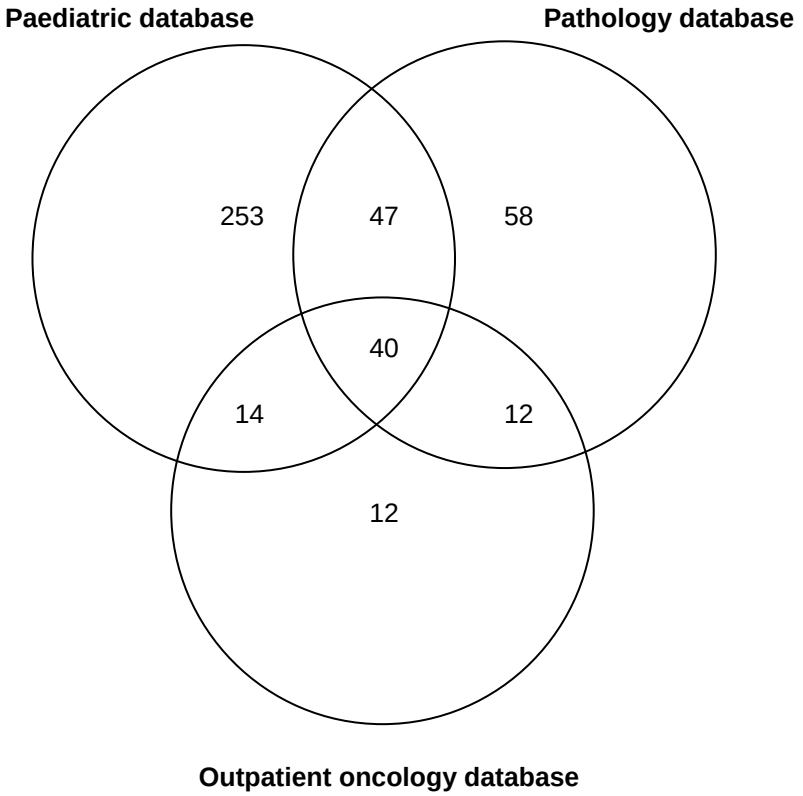


Figure 1. Intersection of the three databases: paediatric database, pathology database and outpatient oncology database (n=436).

The completeness of the separate databases differed. A total of 436 children initially attended the inpatient clinic and had their diagnosis confirmed by pathologists. However, the paediatric database missed 82 (19%) children, who were either never registered or whose medical records were lost. The electronic pathology database missed 279 (64%) children who were never registered although the pathologists sent written reports on them to the paediatrician. During the 3 years since the outpatient clinic started in 2007, 325 children were diagnosed with cancer but the outpatient oncology database missed 247(76%) children: these children either never attended the outpatient clinic (because they abandoned treatment, died or only required inpatient care) or were never registered.

The 436 patients consisted of 256 (59%) boys and 180 (41%) girls and the male/female ratio was 1.4:1. The number of new childhood cancer patients seen in MTRH ranged from 103 to 115 annually for the 4-year period (figure 2), with a yearly average of 109 patients.

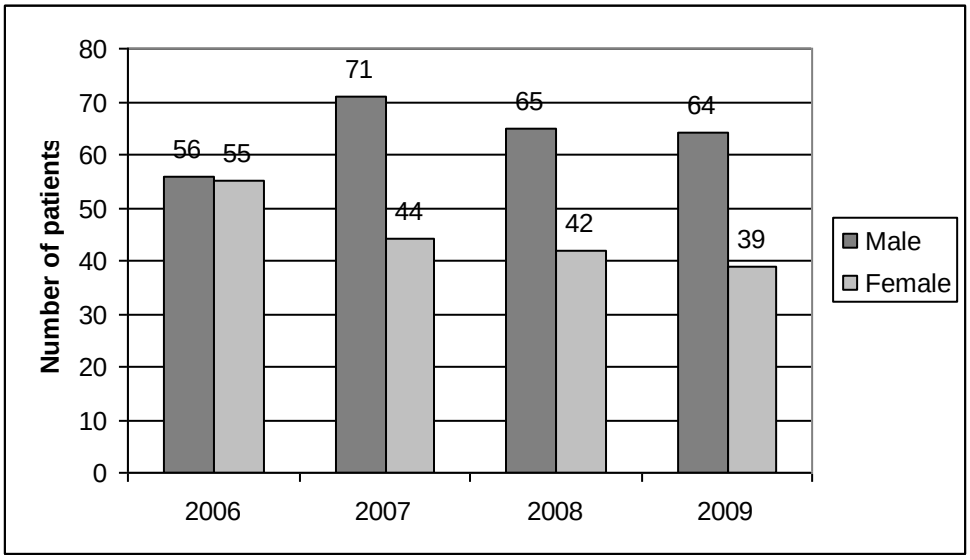


Figure 2. Male and female childhood cancer patients diagnosed annually at Moi Teaching and Referral Hospital, Kenya (n=436)

Age at admission was recorded in 426 (98%) children and ranged from 0 to 18 years (figure 3). The peak incidence of cancer was in the group aged 6–10 years (29%), mean 8.6 (SD 5.0), median 8. Table 1 presents the difference in expected and reported incidence of childhood cancer per million children under 15 years of age.

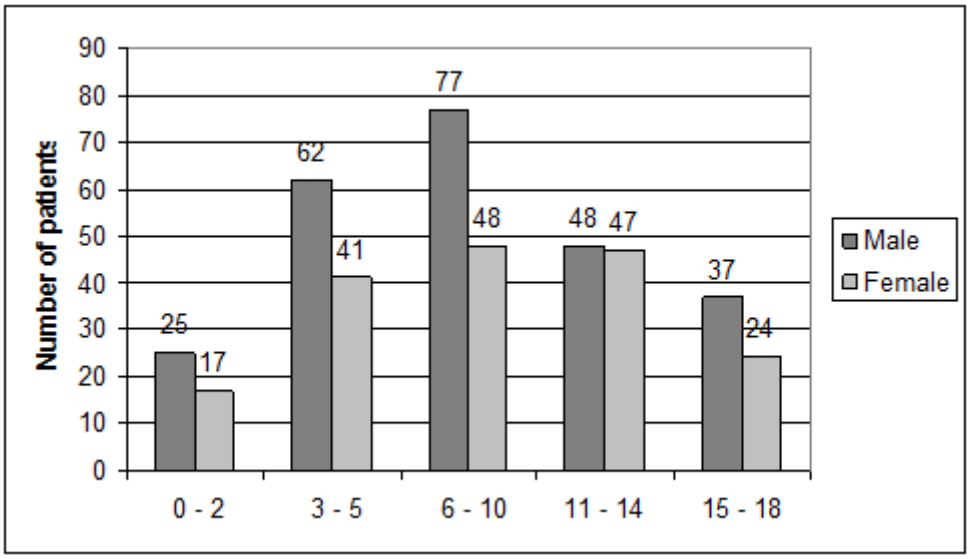


Figure 3. Age and gender at admission of childhood cancer patients diagnosed at Moi Teaching and Referral Hospital,Kenya (n=426)

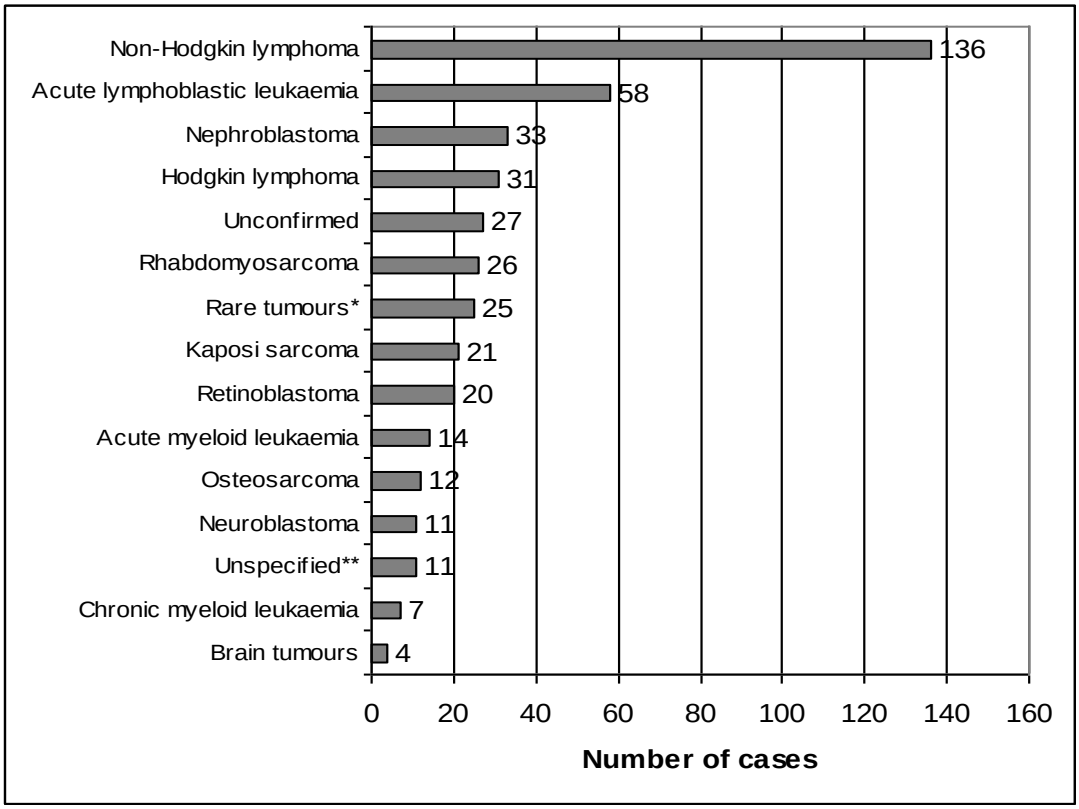
Table 1. Expected and reported incidence of childhood cancer per million children less than15 years old

Area	Cancer incidence	Leukaemia incidence	Nonleukaemia incidence
Expected in high-income countries	130* (100%)	41* (32%)	89* (68%)
Expected in low-income countries	102* (100%)	16* (16%)	85* (83%)
Reported in service area of MTRH, Western Kenya	13 (100%)	2 (15%)	11 (85%)

*Data source: Howard SC et al[9] and Parkin et al.[11]

Figure 4 shows the distribution of the different types of cancer. A similar distribution of diagnoses was found in the three databases. Of all 436 children, in 11 (3%) only the primary site of the malignancy was known (such as the kidney), in 27(6%) a specific diagnosis was not confirmed and in 398 (91%) a specific diagnosis was made. Of these 398 children, 246 (62%) had haematological malignancies, 4 (1%) brain tumours, 123 (31%) solid tumours and 25 (6%) rare tumours.

Two types of haematological malignancies are responsible for almost half of all cases of childhood cancer in MTRH. Non-Hodgkin's lymphoma is by far the most common type of cancer (34%), followed by acute lymphoblastic leukaemia (15%), Hodgkin's lymphoma (8%), acute myeloid leukaemia (4%) and chronic myeloid leukaemia (2%). Brain tumours included glioma (0.5%), astrocytoma (0.3%) and medulloblastoma (0.3%). Solid tumours consisted of nephroblastoma (8%),rhabdomyosarcoma (7%), retinoblastoma (5%), Kaposi's sarcoma (5%), osteosarcoma (3%) and neuroblastoma (3%). Rare tumours included nasopharyngeal carcinoma (2%), germ cell tumours (2%), hepatoblastoma (0.5%), hepatocellular carcinoma (0.5%) and follicular thyroid carcinoma (0.3%).



* Such as nasopharyngeal carcinoma, germ cell tumours, hepatoblastoma, hepatocellular carcinoma and follicular thyroid carcinoma.

** Only the primary site of the malignancy was known, for example "renal tumour".

Figure 4. Distribution of childhood cancers between 2006-2010 (n=436)

DISCUSSION

The area served by MTRH suggests that the number of paediatric patients with cancer is many times larger than the annual average of 109 patients who visit the hospital.[9–11]

There are numerous reasons why there are fewer reported than actual cases of childhood malignancies in low-income countries. Cancer cases can only be identified after diagnosis and accurate registration.[9,12] Lack of parental education and low awareness of health issues delay seeking of medical help. Parents may not recognise symptoms of paediatric malignancies, or may believe cancer is incurable and therefore do not seek medical care.[9 12 13] Parents may rely on traditional healers using herbs or witchcraft.[14] Parents may not have a means of transport to a medical centre, or may not be able to pay for diagnostic procedures or treatment.[15 16] Healthcare providers may not be skilled in recognising childhood cancer, and laboratory and imaging devices may be lacking.[9 12] Personnel may also believe that

cancer is incurable or that parents cannot afford treatment and therefore decide referral or treatment is not worthwhile.[17 18] And if malignancies are accurately diagnosed, they may not be registered systematically.[9] Each misstep can prevent documentation of cases, and results in a lower reported than actual incidence of cancer. These difficulties may be overcome by increasing public awareness of the symptoms, diagnosis and treatment of childhood cancer, emphasizing the fact that most cancer can be cured, facilitating access to medical services for poor families, training healthcare providers, enhancing diagnostic capacities and rigorously improving record-keeping.

The distribution of malignancies in Western Kenya is similar to findings in other equatorial African countries but differs markedly from studies performed in high-income countries.[12 19–25] Such differences may be the result of the cumulative effect of variable genetic predisposition, infectious diseases, environmental exposures and inaccurate registration.[26] In high-income countries, haematological malignancies are the most common, followed by brain tumours and solid tumours.[9–11] Our study reveals that haematological malignancies in Western Kenya are also the most prevalent cancers. However, in high-income countries acute lymphoblastic leukaemia is the most common haematological cancer, whereas in Kenya it is non-Hodgkin's lymphoma. Very few brain tumours are registered at MTRH. The substantial under-estimation of brain tumours in low-income countries may be related to scarcity of the neuro-imaging facilities required for diagnosis and limited possibilities to perform tumour biopsies, and requires further exploration in the future.[27] The group of solid tumours encompasses the second largest group of cancers in Kenya.

Our study showed that non-Hodgkin's lymphoma was the most common type of cancer in MTRH. In Kenya, Burkitt's lymphoma, a subtype of non-Hodgkin's lymphoma, is much more prevalent than in high-income countries due to increased infection rates with Epstein–Barr virus and immune stimulation by malaria.[28-31] However, pathologists in MTRH are unable to distinguish Burkitt's lymphoma from other non-Hodgkin's lymphomas because fine needle aspirates are used for diagnosis, facilities for additional staining are lacking and technical challenges hinder the reading of slides.

We found a relatively low rate of acute lymphoblastic leukaemia. The difference between the reported and actual incidence of childhood malignancies in low-income countries is most striking for leukaemia,

the symptoms of which resemble those of infections including malaria, and children can die before cancer is suspected or diagnosed. In lymphomas and solid tumours, visible symptoms encourage parents to seek medical help and early death is less common.[9]

We also found high numbers of retinoblastoma and Kaposi's sarcoma. Non-heritable retinoblastoma has a higher incidence among less affluent populations, suggesting an association with poor living conditions and an infectious aetiology. The high rate of Kaposi's sarcoma in Kenya is due to the high percentage of HIV-positive children.[8 32–35] In one of our studies at MTRH, we found that 13% of childhood cancer patients were HIV-positive and that 57% of these HIV-positive children were diagnosed with Kaposi's sarcoma (unpublished data).

The absence of Ewing's sarcoma in MTRH is remarkable. In low-income countries a very low incidence of a particular malignancy may indicate systematic misdiagnosis, especially among malignancies that are difficult to identify without expertise and pathological diagnostic facilities. When Ewing's sarcoma, for instance, is often misdiagnosed as rhabdomyosarcoma, the rate of Ewing's sarcomas is strikingly low while that of rhabdomyosarcoma is remarkably high. This necessitates further investigation at MTRH. The diagnosis of certain tumour types may be limited by lack of access to specialized diagnostic stains.[9]

Our finding that more males than females develop cancer is in accordance with earlier studies in Africa, but is unexplained. It is known that slightly more males have cancer and that boys are more susceptible to Burkitt's lymphoma than girls. Some studies suggest that sex chromosome linked genes may play a role in the latter.[12 20–23] Other possible explanations for male preponderance are cultural and economic. Parents may consider that boys are more important for the family, contribute more to society and will take care of their aging parents, leading to more frequent presentations of boys than girls to healthcarecentres.[23 36]

Our study shows that there is a wide age distribution of malignancies in Kenya. This pattern is also found in other African countries but differs from that of high-income countries. In high-income countries most childhood cancers occur in children under 5 years of age, decrease between 6 and 14 years of age and increase again between 15 and 18 years of age.[10 11] However, the largest group of children attending

MTRH are between 6 and 10 years old, perhaps because the majority of children with acute lymphoblastic leukaemia (aged 3–6 years) die of complications before reaching hospital. In addition, parents are aware of the high death rate of children and so if those below 6 years of age fall seriously ill, more parents are resigned to the fact that they will die. However, when children are older they start to contribute to the family income and medical help will be sought sooner. The group of children aged 15–18 years with cancer is quite small.

Gathering data in a low-income country like Kenya posed several difficulties. Filling in of medical records is often not seen as a priority, and storage space is insufficient and frequently changed. Thus medical records were at times mixed up in piles in remote rooms which had not been opened for years. Many medical records were missing, while the records themselves were in poor condition, falling apart and missing notifications because papers had been torn from the files. Important information was either not categorised by date and issue or not documented at all. If medical records are unorganised, the status of patients is very difficult to monitor. Overall, getting access to medical records and extracting reliable data took substantial effort.

Before this study was carried out, information on patients was not gathered in a comprehensive or systematic manner at MTRH. None of the three databases was complete, indicating that the thoroughness and quality of the data sources require profound improvement: for example, all children in whom a malignancy is confirmed need to be recorded in the pathology database.

Our study provides an overview of childhood cancer patients presenting for treatment in Western Kenya over 4 years. We cannot confirm that we succeeded in collecting the names ofall childhood cancer patients. However, local caregivers believe that we assembled the vast majority of fi les and that we are able to provide a reliable overview. Basic data for childhood cancer patients must be collected before improvements can be made. We also learned that more research on non-Hodgkin's lymphoma is advisable. This type of cancer, when diagnosed at an early stage, has a high cure rate, and so treating it successfully would demonstrate that cancer can be cured in Kenya and encourage patients, parents and medical staff. MTRH should continue and extend the new comprehensive cancer registration system to serve as the basis for an evidence-based oncology program, which may lead to better clinical results.[9]

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CHAPTER 3

ABANDONMENT OF CHILDHOOD CANCER TREATMENT IN WESTERN KENYA*

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ABSTRACT

Background: *The most important reason for childhood cancer treatment failure in low-income countries is treatment abandonment.*

Objective: *The aim of this study was to explore reasons for childhood cancer treatment abandonment and to establish the condition of these children.*

Design: *This was a descriptive study using semi-structured questionnaires. Home-visits were conducted to interview families of childhood cancer patients, diagnosed between January 2007 and January 2009, who had abandoned treatment at the Moi Teaching and Referral hospital (MTRH).*

Results: *Between January 2007 and January 2009, 222 children were newly diagnosed with a malignancy at MTRH. Treatment outcome was documented in 180 patients. Of these 180 patients, 98 (54%) children abandoned treatment. From December 2011 till August 2012, 53 (54%) of the 98 families were contacted. Due to lack of contact information 45 families were untraceable. From 53 contacted families, 46 (87%) families agreed to be interviewed. Reasons for abandonment were reported by 26 families and they were diverse. Most common reasons were: financial difficulties (46%), inadequate access to health-insurance (27%) and transportation difficulties (23%). Most patients (72%) abandoned treatment after the first 3 months had been completed. Of the 46 children who abandoned treatment, 9 (20%) were still alive: 6 (67%) of these children looked healthy and 3 (33%) ill. The remaining 37 (80%) children had passed away.*

Conclusion: *Prevention of childhood cancer treatment abandonment requires improved access to health-insurance, financial or transportation support, proper parental education, psychosocial guidance and ameliorated communication skills of health-care providers.*

Abbreviations: *MTRH - Moi Teaching and ReferralHospital; NHIF – NationalHospital Insurance Fund*

What is already known on this topic: *a) Abandonment of childhood cancer treatment is a major contributor to treatment failure in low-income countries and virtually unknown in high-income countries; b) The reasons for treatment abandonment are documented in high-income countries and low-income countries in Central America and Asia.*

What this study adds: *a) This study highlights the reasons for abandonment in a population based in Africa. b) Given the different sociocultural setting, the reasons and the timing of the abandonment are unique to this setting. This may provide information that is crucial in setting up intervention programmes to minimise abandonment in Africa.*

INTRODUCTION

Approximately 200 000 children and adolescents are diagnosed with cancer every year worldwide. Low-income countries bear the burden of childhood cancer accounting for 80% of cases and 90%of mortality. This poor outcome results from different factors, including late presentation, limited access to curative therapies, suboptimal supportive care and treatment abandonment.[1–4]

Treatment abandonment is a major contributor to treatment failure in low-income countries accounting for up to 50–60% of cases. On the contrary, this phenomenon is virtually unknown in high-income countries.[5–10]

Studies focusing on reasons for treatment abandonment among childhood cancer patients are scarce and absent for Africa.[11] The most important reason for childhood cancer treatment failure in the Moi Teaching and Referral Hospital (MTRH)in Western Kenya is abandonment of treatment whereby 54% of all families prematurely stop prescribed treatment.[12] Insight into the reasons of families to abandon treatment is urgently required and will guide interventions aimed at avoiding abandonment.

The aim of this study was to interview parents of children who had abandoned cancer treatment to explore their reasons for abandonment and to assess the clinical condition of the children.

METHODS

Setting

Our study was carried out in Kenya, a country located in Eastern Africa. Kenya has 41 million inhabitants. Half of all citizens live below poverty line.[13]

The service area of MTRH is vast. The estimated population served is 16-18 million people and 100-120 children are diagnosed with cancer at this institution every year. [14] The hospital has a bed capacity of 700 patients of which 72 are in the pediatric department. This department includes 12 beds reserved for pediatric oncology, where there are commonly two oncology patients per bed.

The National Hospital Insurance Fund (NHIF) is the most common health-insurance in Kenya. It is available for every Kenyan resident above 18 years. The insurance covers the member and family. NHIF-members who are not employed or are self-employed pay 1.4 Euro

(Ksh.160) per month. NHIF-members who are employed, pay a variable amount depending on their salary.[15] Less than 10% of Kenyan population is enrolled in NHIF[16,17]

Study Design

A descriptive study was conducted. Home visits were made to families whose children were diagnosed between January 2007and January 2009 and had abandoned treatment. In line with International Society of Paediatric Oncology (SIOP) recommendations,[10] treatment abandonment was defined as failure to start or continue treatment during four or more consecutive weeks. Home visits were conducted from December 2011 until August2012.

Places of residence and telephone numbers were retrieved from medical records. Families were contacted by phone to make an appointment for the interview. In case telephone contacts were missing, the place of residence was visited and neighbours or relatives were asked for contact details of the family. In case the family was not traceable by phone or residence visit, we requested the region's community leaders to help find the family involved.

Semistructured questionnaires and observations of living circumstances were conducted by an independent, trained interviewer and assistant.

Interviews focused on reasons for abandonment and condition of each child after discontinuing treatment. A panel of doctors and psychologists assured clear coherent questions. The questionnaire was pilot-tested for its content, clarity and cultural sensitivities on five families and revised accordingly. Family living circumstances were observed to gain insight about socioeconomic and housing conditions.

Respondents rendered informed consent. Anonymity and confidentiality were assured. The study was endorsed by the Research Ethics Committee of MTRH.

Data Analysis

Frequency distributions, median, means and SDs were assessed for each variable. Differences in socio-demographic and clinical characteristics between respondents and non-respondents were compared using $\chi 2$, Fisher's exact and t tests. Fisher's exact test for variables with more than two categories was performed in R V.2.15.0.

p Values (two-sided) were considered statistically significant if <0.05. Data management and analysis were performed using SPSS**.**

RESULTS

Patient and Parent Characteristics

Between January 2007 and January 2009, 222 children were newly diagnosed with a malignancy at MTRH. Treatment outcome was documented in 180 patients. Of these 180 patients, 98 (54%) children abandoned treatment.5 Boys abandoned treatment slightly more often, but this difference did not reach statistical significance (p=0.078).

From December 2011 until August 2012, we were able to contact 53 (54%) of 98 families: 64% directly by phone, and 36% through intervention of region's community leaders. Due to lack of contact information, 45 families were untraceable. From 53 contacted families, 46 (87%) families agreed to be interviewed and 7 (13%) families refused to participate. No significant differences in age, gender or type of cancer were found between group of children whose families could or could not be contacted.

Table 1 presents socio-demographic characteristics. Duration between interview and abandonment ranged from 25 to 64 months, median 44 months. Figure 1 shows the distribution of different types of cancer. Table 2 illustrates living circumstances of families concerned.

Table 1. Socio-demographic characteristics

Characteristics (n=46)	
Age: mean ± SD (years)	9.2 ± 5.0
Gender: male	33 (72%)
Fathers' educational level* (n=38):	
Low (no education, primary school)	19 (50%)
Intermediate (high school)	15 (39%)
High (university or other tertiary institute)	4 (11%)
Mothers' educational level** (n=43):	
Low (no education, primary school)	31 (72%)
Intermediate (high school)	11 (26%)
High (university or other tertiary institute)	1 (2%)
Fathers' profession* (n=38):	
Farmer	19 (50%)
Laborer/ irregular job	10 (26%)
Regular job	9 (24%)
Mothers' profession** (n=43):	
Housewife	17 (40%)
Farmer	20 (47%)
Laborer/ irregular job	4 (9%)
Regular job	2 (5%)
Respondents:	
Both parents	16 (35%)
Mothers	15 (33%)
Fathers	9 (20%)
Siblings	3 (7%)
Other caregivers	3 (7%)

* The identity of 8 fathers was unknown according to the mothers.
** Background information of 3 mothers was unknown according to the interviewees: 2 of these mothers had passed away and 1 mother had been expelled from the family.

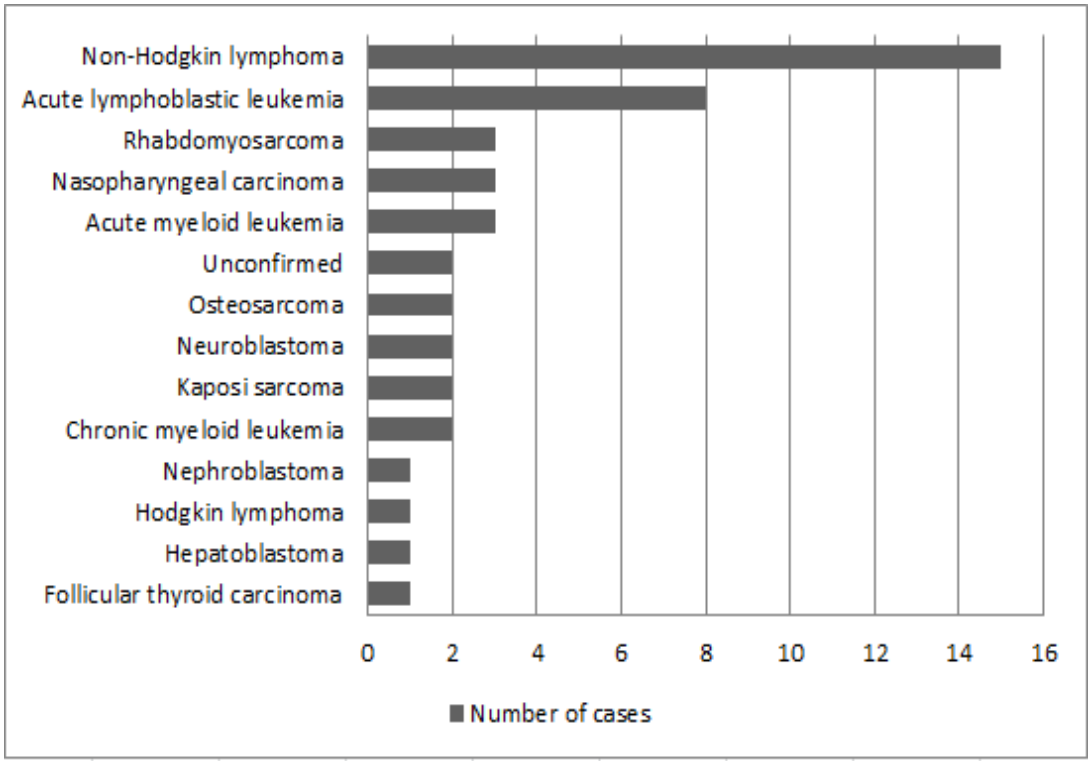

Figure 1. Distribution cancer types of Kenyan childhood cancer patients (n=46) who abandoned treatment

Table 2. Observations of family living circumstances of Kenyan childhood cancer patients (n=46) who abandoned treatment

Living circumstances	**Total N (%)**
Total number of household members: mean ± SD	7.4 ± 2.8
Estimated total size of living space in square meters: mean ± SD	27.6 ± 7.4
Ownership of land	42 (91%)
Estimated total size of land in acres: mean ± SD	8.4 ± 22
Total possession of live-stock:	41 (89%)
Chicken	39 (85%)
Cow	28 (61%)
Goat	9 (20%)
Sheep	8 (17%)
Donkey	1 (2%)
* Floor condition:	
Soil	11 (24%)
Mud	19 (41%)
Concrete	16 (35%)
Ceramic tiles	0 (0%)
* Roof condition:	
Grass	3 (7%)
Iron sheets	43 (93%)
Tiles	0 (0%)
* Walls condition:	
Mud	33 (72%)
Wood	2 (4%)
Stone	11 (24%)
* Main source of water:	
River/ stream	24 (52%)
Well/ pump	14 (30%)
Waterbasin (pond)	2 (4%)
Tapwater	6 (13%)
* Connection to electricity:	3 (7%)
Possession of refrigerator:	0 (0%)
Cooking facilities:	
Firewood	39 (85%)
Charcoal	4 (9%)
Kerosene	3 (7%)

* Housing conditions [7] were classified as either poor or good based on 5 determinants: 1) floor condition, 2) roof condition, 3) walls condition, 4) main source of water, and 5) connection to electricity. Families were categorized as having a good housing condition if at least 4 of following conditions were present: floor made of ceramic tile; roof of tiles; walls of stones; main source of water is tapwater, and/or connection to electricity. Housing conditions were classified as poor in all 46 (100%) families.

Decision to Abandon Treatment

The decision to abandon treatment was made by both parents (26%), doctors (13%), grandparents (7%), relatives (4%), patient (2%), father (2%), combination of mother/doctor/patient (2%). Twenty (43%) respondents had difficulties answeringthis question. These parents felt strongly that they had done everything in their power to save their child's life and never made a decision to abandon treatment. However, treatment had been interrupted for more than 4 weeks and by definition these families did abandon treatment. Only one family came back for treatment 4 months after initial abandonment..

Patient Condition after Abandonment

Parents stated that the condition of their children at time of treatment abandonment was good (43%) and not good (57%). Their child's condition deteriorated within several weeks or months of abandonment in 87% of cases and stayed good in 13%.

During the home visits, we found that 20% of children were still alive 35–64 months after abandoning treatment: 67% looked healthy and 33% ill. The other 80% of children had died. Duration between treatment abandonment and death ranged between 0 and 14 months. Table 3 shows the fate of patients per treatment duration in which abandonment took place.

Table 3. Fate of Kenyan childhood cancer patients (n=46) per treatment duration in which abandonment took place

Treatment duration at time of abandonment	**Total N (%)**	**Fate N (%)**		
		Deceased	**Alive healthy***	**Alive sick****
At diagnosis	**2 (4%)**	0 (0%)	2 (100%)	0 (0%)
< 1 month	**4 (9%)**	2 (50%)	1 (25%)	1 (25%)
1-3 months	**7 (15%)**	4 (57%)	1 (14%)	2 (29%)
3-6 months	**11 (24%)**	10 (91%)	1 (9%)	0 (0%)
> 6 months	**17 (37%)**	17 (100%)	0 (0%)	0 (0%)
Unclear	**5 (11%)**	4 (80%)	1 (20%)	0 (0%)
Total	**46 (100%)**	**37 (80%)**	**6 (13%)**	**3 (7%)**

* Hodgkin lymphoma (n=2), non-Hodgkin lymphoma (n=1), rhabdomyosarcoma (n=1), follicular thyroid carcinoma (n=1) and unconfirmed diagnosis (n=1). * Non-Hodgkin lymphoma (n=1), nephroblastoma (n=1) and acute myeloid leukemia (n=1).

Reasons for Abandonment

Only 26 (57%) families could report reasons for abandonment. Reasons of families were diverse. Table 4 illustrates that the most common reasons were financial difficulties, inadequate access to NHIF and transportation difficulties.

Table 4. Reasons cited by Kenyan parents of childhood cancer patients (n=26) for abandonment of treatment

Reasons	N (%)*
Financial difficulties	12 (46%)
Inadequate access to NHIF	7 (27%)
Transportation difficulties	6 (23%)
Doctors told parents nothing could be done	4 (15%)
Lack of social support/ pressure from social network	3 (12%)
Child's condition showed no improvement	3 (12%)
Parents preferred treatment elsewhere	2 (8%)
Dissatisfaction with health-care providers	2 (8%)
Belief that cancer is not curable	2 (8%)
Preference for alternative treatment	2 (8%)
Emotional condition child	2 (8%)
Child's wish to abandon treatment	2 (8%)
Post-election violence	2 (8%)
Doctors told parents to leave	2 (8%)
Lost hospital card and refused admittance to MTRH	1 (4%)
Unclear information about diagnosis and treatment	1 (4%)
Long delays in hospital	1 (4%)
Child appeared healthy	1 (4%)
Painful bone-marrow punctures	1 (4%)

* Number of parents that reported the reason. Each patient could have more than one reason. Most parents (62%) reported several reasons.

Financial Difficulties

The most common reason for families to abandon treatment was financial difficulties (46%). During treatment, 30% of all families had a regular income, and 70% did not. The main economic provider was father (74%), extended family (13%), mother (9%) or both parents (4%). The average family income was 40 Euro per month (Ksh 4400). Most families (91%) owned land, and 57% reported that their land was not taken care of when parents stayed with their child in hospital. Since the start of treatment, family's income decreased in 85% of cases because parents had to accompany their child to hospital and therewith lost daily wages or harvest from land. To solve their financial difficulties, families (74%) had to sell valuables: livestock, land, produce of land, household goods. Some families (15%) held a community fundraising, called 'Harambee'. Many families (67%) ended

up in debts, and of these families 52% still have not been able to pay off these debts 4–5 years after the start of treatment.

Inadequate Access to NHIF

The second most common reason for treatment abandonment was inadequate access to NHIF (27%). Figure 2 illustrates that 22% of families had NHIF before they came to MTRH, and 78% did not. Figure 2 also shows the changes in NHIF status of families that did not have insurance at diagnosis.

Of families without NHIF at diagnosis, 75% were informed inside hospital about possibility to apply for NHIF and 25% were not informed. Seventeen (47%) families applied for NHIF, and 19 (53%) families never applied. Ultimately only 33% of children without NHIF at diagnosis received NHIF during treatment. After the application, it took on average 3 months before NHIF started to cover hospital bills.

Summarising, 22 (48%) families had NHIF during treatment: 10 families already prior to treatment and 12 obtained NHIF during treatment. NHIF covered treatment costs partially (77%), completely (18%) and one family did not remember. Twenty-four (52%) families never had NHIF during treatment: 7 families were never informed about this possibility, 12 were informed but never applied and 5 were informed and applied but their child abandoned treatment before NHIF became operational.

Transportation Difficulties

The third most common reason for treatment abandonment was transportation difficulties (23%). Distance to hospital was <50 km (22%), 50–100 km (30%) and >100 km (48%). Mode of transportation used to reach hospital was public transport (46%), walking/public transport (39%), renting a vehicle (13%) and taxi (2%). Travel time to reach hospital varied from <1 h (11%), 1–3 h (50%) and >3 h (39%). Travelling to hospital was considered to be expensive (85%), time consuming (65%) and difficult (37%).

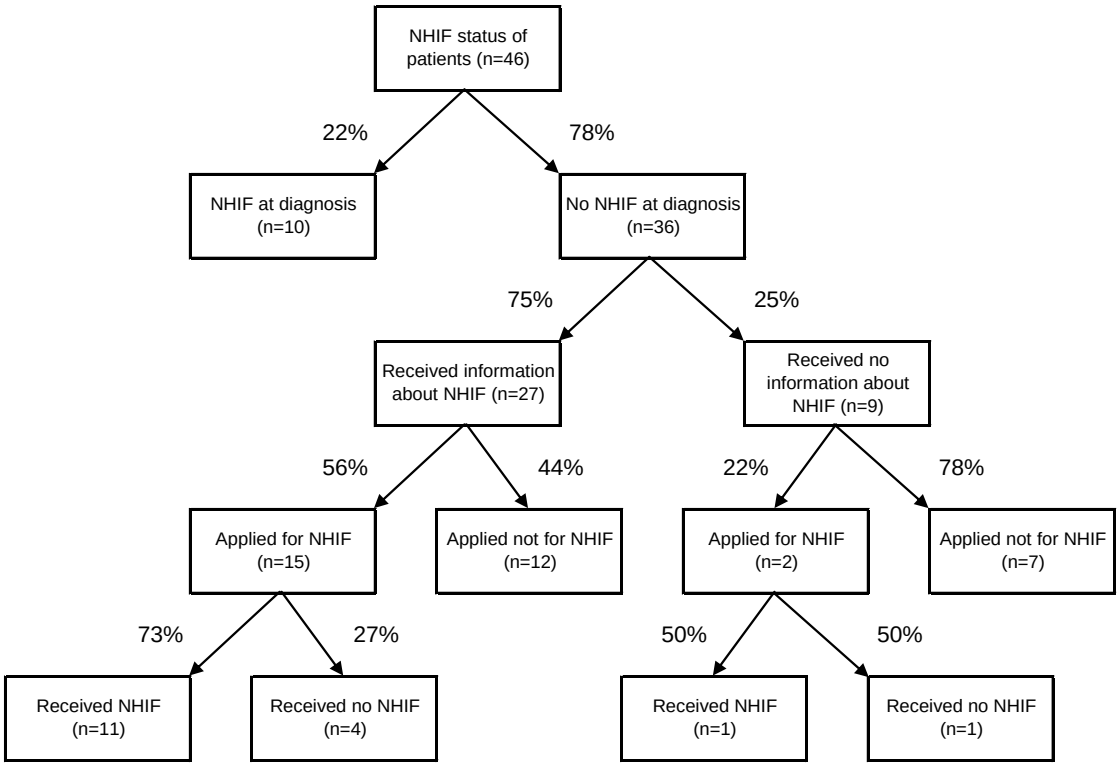

Figure 2. National Hospital Insurance Fund (NHIF) status of Kenyan childhood cancer patients (n=46) who abandoned treatment

DISCUSSION

The treatment abandonment rate of 54% in MTRH is similar to what has been reported in other studies in low-income countries.[18–20] This study involved home visits of families in Kenya whose children had abandoned treatment. To the best of our knowledge, this is the first study of its kind carried out in Africa as regards paediatric oncology.[11] The reasons given for abandonment were diverse, and the majority of families gave more than one reason. Most common reasons were financial difficulties, inadequate access to health insurance and transportation difficulties. The vast majority of patients abandoned treatment after the first 3 months had been completed. Of the 46 children who had abandoned treatment, 20% were still alive and 80% had passed away.

Financial difficulties were the leading cause of treatment abandonment. However, less than half of all families reported it as the reason for abandonment and only two reported it as the only reason for drop-out. These numbers are actually remarkably low given the very poor living circumstances of families involved. Other studies have also reported financial difficulties as one of the top reasons for abandonment.[8 21 22]

Inadequate access to NHIF was the second most common reason cited for treatment abandonment. Twenty-two per cent of families had NHIF before they came to MTRH. Only 15% of families had been informed about NHIF immediately at diagnosis. Families considered the application procedure to be elaborate. Ultimately only 33% of children without NHIF at diagnosis received NHIF during treatment. After completing the application, it took 3 months on average before NHIF started to cover hospital bills. Much progress can be made in this barrier to care, particularly because the national health insurance in Kenya is quite affordable even to families in the lowest income strata.[15] NHIF could provide a significant financial relief to families.

Transportation difficulties were the third most common reason for abandonment. The vast majority of families lived more than 50 km from hospital and used public transport to get to MTRH. Public transport in Kenya is fairly disorganised and does not follow any specific timetables. Vehicles can change routes midway in the journey and increase fares without any prior notice. People who are already strained financially by the disease may be unable to afford the increased cost of transportation to and from hospital. Having satellite clinics or opening up regional cancer centres could help in reducing transportation difficulties. An alternate solution is accommodation for families near MTRH.[23]

The other reasons for treatment abandonment were very diverse, but clearly demonstrate that there is much room for improvement as healthcare providers themselves can help overcome most of these problems by better patient and family education (eg, belief that cancer is not curable, preference for alternative treatment, unclear information about diagnosis and treatment, long delays experienced in the hospital and painful bone marrow punctures).

Sixty per cent of families abandoned treatment more than 3 months after diagnosis. This is very unusual compared with previous studies where abandonment predominantly occurs at diagnosis or in the very first weeks of treatment.[8 11 20] This delayed abandonment is mainly a result of hospital policies in Kenya where patients are retained until their hospital bill is either paid or waived.[12 24–26] In practice this means that initially nearly all patients receive medical care. It is only later when families are confronted with a huge hospital bill that they decide to stop treatment. Many families may also not be able to confront doctors at the beginning of therapy that they want to abandon therapy because

doctors are generally treated with high regard in Kenyan society and it would be culturally unacceptable for patients to question or disagree with physicians. After going home, families may also decide not to return for medical care due to social pressure. The communities may doubt the curability of cancer and recommend alternative medicine.[12]

This study made apparent that the topic of treatment abandonment is very sensitive. Although we tried our best to explainthat we certainly did not blame the families, parents may nevertheless have felt uncomfortable or guilty. Only 57% of families confirmed that they had prematurely stopped treatment and could give their reasons for it. As per the preliminary findings of a study we have recently conducted at MTRH, the parents may not be adequately informed about the duration of treatment and the need to complete it. Consequently, parents may not be aware that they stopped treatment prematurely. In low income countries, information provision to poor families in public hospitals is not given priority.[7 8 19 27]

Interestingly families of six children said that healthcare workers suggested that they should stop therapy. Both families and medical records suggest that this advice was not always based on a dismal condition or prognosis. The advice may be due to the fact that some healthcare providers in MTRH do not believe in the curability of cancer and realise that families will be faced with many socioeconomic and emotional hardships if they continue treatment. Given the historically poor survival rates of childhood cancer in low-income countries, this impression is understandable, but a mind shift is required.

Various limitations were encountered during the course of this study. The study was carried out several years after diagnosis. This made it quite difficult to trace families due to missing or outdated contact information in medical records. Consequently, we were only able to reach half of all targeted families. The fact that some families declined to participate in the interviews may also have had an impact on the results of this study.

Based on the findings of this study, we recommend that governments ensure that more families get enrolled in health insurance as this is likely to have a great impact on outcomes of childhood cancer.12 Citizens should be actively encouraged or required to take health insurance. The application procedure should be simplified and personnel assigned to facilitate the process. Healthcare providers

themselves can also facilitate access to health insurance. Every family should be educated immediately at diagnosis, both verbally and in writing, about the advantages. Satellite clinics or a guesthouse for families would alleviate transportation difficulties. A system to pay for the transport needs of families would also be useful. There is need for healthcare providers to improve on their attitude and communication skills. Proper parental education and psychosocial support is essential to convince families to adhere with therapy.[27 28]

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CHAPTER 4

INFLUENCE OF HEALTH-INSURANCE ACCESS AND HOSPITAL RETENTION POLICIES ON CHILDHOOD CANCER TREATMENT IN KENYA‡

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ABSTRACT

Background: *Kenyan national policies for public hospitals dictate that patients are retained on hospital wards until their hospital bills are paid, but this payment process differs for patients with or without access to National Hospital Insurance Fund (NHIF) at diagnosis. Whether these differences impact treatment outcomes has not been described. Our study explores whether childhood cancer treatment outcomes in Kenya are influenced by health insurance status and hospital retention policies.*

Procedure*: This study combined retrospective review of medical records with an illustrative case report. We identified children diagnosed with malignancies at a large Kenyan academic hospital between 2007 and 2009, their treatment outcomes, and health-insurance status at diagnosis.*

Results: *Between 2007 and 2009, 222 children were diagnosed with malignancies. Among 180 patients with documented treatment outcome, 54% abandoned treatment, 22% had treatment-related death, 4% progressive/relapsed disease, and 19% event-free survival. Health-insurance status at diagnosis was recorded in 148 children: 23% had NHIF and 77% had no NHIF. For children whose families had NHIF compared with those who did not, the relative risk for treatment abandonment relative to event-free survival was significantly smaller (relative-risk ratio=0.31, 95% CI=0.12–0.81, P=0.016). The case report illustrates difficulties that Kenyan families might face when their child is diagnosed with cancer, has no NHIF, and is retained in hospital.*

Conclusions: *Children with NHIF at diagnosis had significantly lower chance of abandoning treatment and higher chance of survival. Childhood cancer treatment outcomes could be improved by interventions that prevent treatment abandonment and improve access to NHIF. Hospital retention of patients over unpaid medical bills must stop.*

Abbreviations: *MTRH - Moi Teaching and ReferralHospital; NHIF - NationalHospital Insurance Fund*

INTRODUCTION

In high-income countries, nearly 80% of children with cancer can be cured. However, only 20% of children affected worldwide live in high-income countries and benefit from best available therapies. The vast majority of childhood cancer patients reside in low-income countries and have little chance of survival. This discrepancy in survival between high- and low-income countries is largely attributable to treatment abandonment. This phenomenon is almost non-existent in high-income countries [1–6]. The International Society of Pediatric Oncology has declared that treatment abandonment can no longer be disregarded [7].

At Moi Teaching and Referral Hospital (MTRH) in Kenya insight into childhood cancer treatment outcomes was missing. However, locally involved caregivers recognize abandonment as a major problem. In Kenya, treatment abandonment may be affected by policies impacting access to care, including health insurance and retention of patients in hospitals over unpaid medical bills. Some patients are retained for months [8–10]. Reports of hospital retention come from numerous countries [11–34].

Understanding the impact of treatment abandonment, insurance coverage and hospital retention policies on childhood cancer treatment outcomes may help to design strategies to increase survival rates of children with cancer in low-income countries. Our study explores childhood cancer treatment outcomes and their relationship to health-insurance status at diagnosis and hospital retention policies.

METHODS

Setting

Kenya is a low-income country and 50% of its population lives below the poverty line. In 2009, Kenya had 39 million inhabitants, 42% (16 million) of whom are children under 15 years [35]. Kenya has only two academic hospitals capable of providing oncology patients with locally appropriate multimodal treatment. The first is situated in Nairobi. MTRH, the second academic hospital, is in Eldoret. The study was carried out at MTRH, the only hospital in Western Kenya treating children with cancer. The catchment area of MTRH is 16–18 million people, which comprises 40–45% of all Kenyan inhabitants, including around 7 million children less than 15 years of age. With a childhood cancer incidence in low-income countries of 102 per million children less than 15 years old [36,37], the service area of MTRH would expect to have around 700 childhood cancer patients under 15. In reality, only 110 children are annually diagnosed with a malignancy [38].

The pediatric department at MTRH includes 72 beds, of which 12 are reserved for oncology patients. The pediatric-oncology ward is supervised by one to two pediatricians. Treatment options include surgery and chemotherapy. Radiotherapy is not available.

Hospital Payment Processes

Figure 1 shows two parental payment processes of hospital bill at diagnosis as documented in medical records: (1) National Hospital Insurance Fund (NHIF) or (2) No NHIF. Some families without NHIF need to directly pay the hospital bill; other families will be exposed to the waiving procedure. After completion of waiving procedure, the hospital bill is either: (a) paid by parents, (b) partially paid by parents and partially waived by hospital, or (c) waived by hospital.

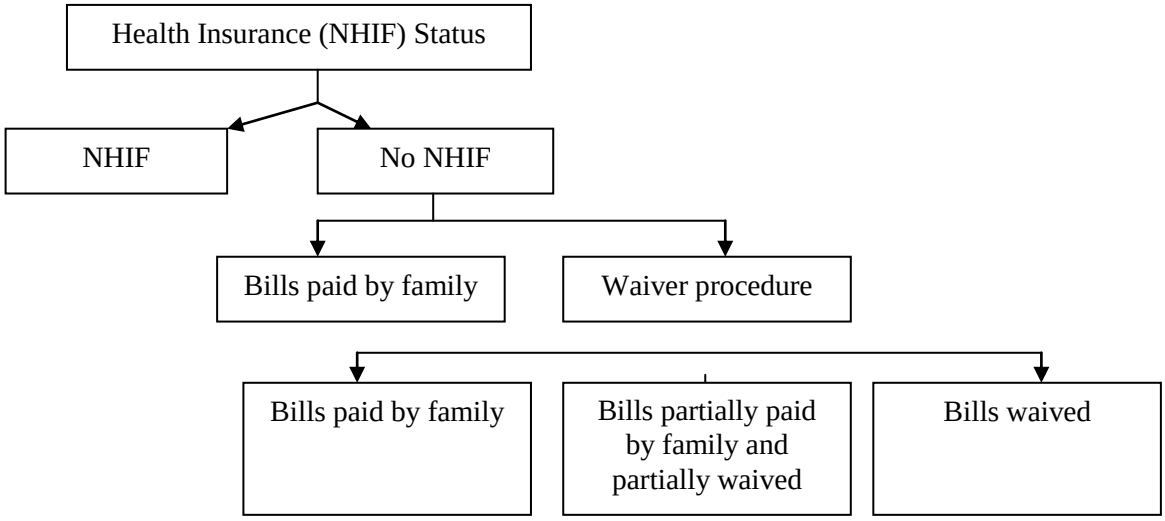


Figure 1. Payment process of hospital bill in public hospitals in Kenya.

National Hospital Insurance Fund (NHIF)

NHIF in Kenya was established in 1966 as a department under the Ministry of Health. NHIF membership is open to all Kenyans who have attained the age of 18 years. Members of NHIF who are not employed or self-employed pay 160 Kenyan Shilling (s1.2) per month for inpatient insurance coverage. Members of NHIF who are employed pay an amount depending on their salary. NHIF provides an inpatient coverage of up to 396,000 Kenyan Shillings (s3,077) per year for contributor, spouse, and children. NHIF reimburses hospital claims as per agreed daily rebates. NHIF can be solicited if a patient is under hospital care. The application process takes 2 months. NHIF will start covering the medical bill once the family is an official member [39]. At MTRH it is not clearly defined who is responsible for guiding the parents in obtaining NHIF.

Retention on Hospital Wards

If a pediatric patient is discharged from hospital by doctors' orders, but their parents cannot pay the hospital bill, the parents are not allowed to take their child home. The hospital retains the child for as long as it takes the parents to pay the hospital bill or until their hospital bill is waived [8–10]. Moreover, every extra day that the child is kept in the hospital adds to the costs for hospitalization. An iron gate with security guards is located at the entrance of the ward to stop parents from leaving with their child before the hospital bill is paid. If parents do escape with their child, the hospital bill must be paid by the security guard, social worker, and sometimes also by the nurse who took care of the child in hospital.

Waiving Procedure

If parents have difficulty paying the costs of treatment in public hospitals in Kenya, the hospital bill can be waived by the waiving procedure [8–10]. Social workers are appointed at wards of public hospitals to implement this waiving procedure. They collect information on the financial situation of family concerned and write a report. The social worker may conduct home visits to explore the socio-economic status of the family and their relatives. During these visits, the social worker is accompanied by security guards. The social worker's report is then presented to a waiver committee composed of representatives of the hospital's legal and and security office, and chaired by the principal administrator in charge of hospital finance and administration. There is no written procedure for waiving involved and there are no criteria, rules, or regulations available.

Study Design

For this study, we combined a retrospective review of the medical records with a case report. For the review of the medical records, we included all children with a newly diagnosed malignancy between January 2007 and January 2009, with treatment outcome documented in the medical records, and who were between 0 and 19 years at diagnosis. The following variables were collected: gender, age at diagnosis, province of origin, duration of symptoms before arrival at MTRH, cancer type, HIV status, treatment outcome, and health-insurance status at diagnosis .Treatment failure was defined as treatment abandonment, treatment-related death, and progressive or relapsed disease. Treatment abandonment was defined as failure to start or continue scheduled curative treatment during 4 or more consecutive weeks [7].

A single case study was performed in follow-up to the retrospective analysis, to elucidate the impact of financial challenges facing families of childhood cancer patients. The investigators identified a single case of childhood acute lymphoblastic leukemia without NHIF at diagnosis. A home visit was conducted in December 2011 to interview the parents. Two independent interviewers used a semi-structured questionnaire .Informed consent was obtained. The case report was checked and endorsed by the family concerned. The study was approved by the Institutional Research Ethics Committee of MTRH.

Data Analysis

Statistical analyses were performed in Stata version 12.0 [40].Multinomial logistic regression was used to compare treatment outcomes between children from families with and without NHIF at diagnosis. Event-free survival was taken as reference category. Multinomial logistic regression was used rather than logistic regression because there were four possible outcome categories. To quantify the difference in risks of outcomes between the NHIF and no NHIF group we computed the relative-risk ratio (RRR) for each of the adverse outcomes (treatment abandonment, treatment-related death, and progressive or relapsed disease) relative to event-free survival. RRR is the ratio of two relative risks of outcome relative to event-free survival for the NHIF and no NHIF group. As missing values occurred for both treatment outcomes and health-insurance status we used multiple imputation, then deletion (MID) [41]. The monotone method was used to impute both treatment outcome and health-insurance status. Each imputation model consisted of a single predictor: age at diagnosis, gender, province of origin, HIV status, or cancer type.

RESULTS

Medical Records Study

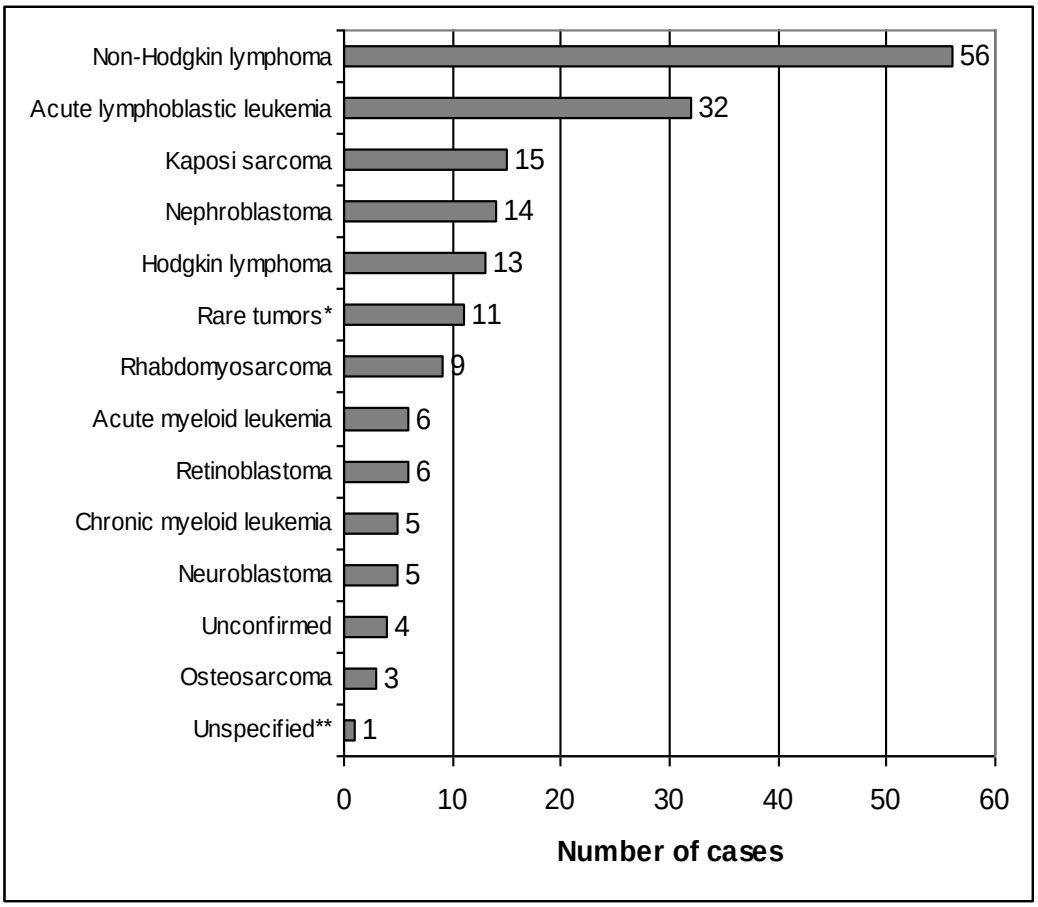
Between January 2007 and January 2009, 222 children were newly diagnosed with a malignancy. Treatment outcomes were documented for 180 (81%) patients. No significant differences were found in types of cancer or gender between groups with or without documentation of treatment outcome. Of the 180 patients, 59% were boys. Peak incidence occurred in the group of 6–10 years old (34%), mean 7.8 (SD=4.9), median 8 years. Province of origin was recorded for 162 (90%) children. All came from the Western part of Kenya: Rift Valley (61%),West Province (35%), and Nyanza (4%).

Table I shows the duration of symptoms before arrival at MTRH (n=144, 80%). Figure 2 shows the distribution of different types of cancer. HIV status was recorded for 161 (89%) children, of whom14% were positive and 86% negative. Of HIV-positive children,57% were diagnosed with Kaposi sarcoma. Figure 3 shows that the most common type of treatment failure was treatment abandonment (54%).

Health-insurance status at diagnosis was recorded for 148 (82%) children: 23% had NHIF and 77% had no NHIF at diagnosis. No significant differences were found in types of cancer or gender between groups with or without NHIF. Table II shows their consecutive treatment outcomes. Multinomial regression evaluating the 148 complete cases showed that the relative risk for abandonment relative to event-free survival was lower for patients with NHIF at diagnosis. Relative risk for death and progressive or relapsed disease relative to event-free survival was not different between groups with and without NHIF at diagnosis. The results were similar after MID, for all single predictor imputation models considered.

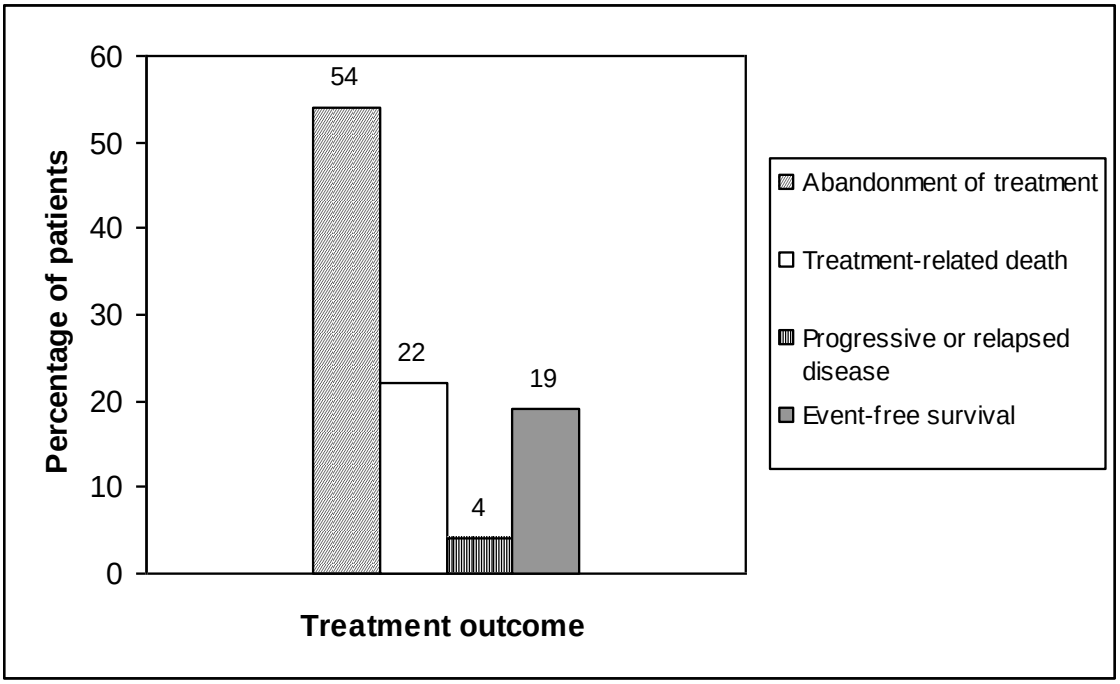
Table I. Duration of symptoms before arrival at MTRH in children with Cancer (n=144)

Duration symptoms before arrival MTRH (months)	N (%)
<1	25 (17)
1–3	54 (38)
3–6	36 (25)
6–9	7 (5)
9–12	4 (3)
≥12	18 (12)



*Such as nasopharyngeal carcinoma, hepatoblastoma, germ cell tumors, hepatocellular carcinoma, and follicular thyroid carcinoma.** Only the originate tissue of the malignancy was known.

Figure 2. Distribution of childhood cancer types between 2007 and 2009 (n=180)



* Abandonment of treatment; refused treatment (10%), initially started treatment (90%)

** Progressive or relapsed disease; progressive disease (50%), relapse (50%)

Figure 3. Treatment outcome in children with cancer (n=180)

Case Report

A 3.5-year-old boy in Kenya was admitted to MTRH with fever and nose bleeds. The diagnosis "acute lymphoblastic leukemia" was confirmed in his medical record, but no health-care provider informed his parents about his diagnosis or the required treatment. A friend told them that their son must have cancer if he was staying on the pediatric oncology ward. The father finally asked a doctor, who told him that his son had leukemia. For 5 months, the boy received cancer treatment at MTRH incurring high costs. The mother stayed with her son during his hospitalization. The boy's grandparents took care of his siblings in her absence. Because his father had to visit MTRH regularly, he lost his job. Subsequently the family's income decreased.

The parents described experiencing severe hardships because they could not afford cancer treatment. The waiving procedure did not entail clear explanations and did not follow written procedure or clear criteria. Social workers made frequent visits to the ward to check on the progress the family had made in getting money for the hospital bill. Social workers were often "harsh and sometimes aggressive." They did not listen to the parents' explanations as to why the family could not pay the bills. When doctors wanted to discharge the little boy, the parents were not allowed

to take their son home because the hospital bill was not paid. The father describes the hospital retention and waiving procedure as “psychological torture.” The hospital bill adds up while families go out to look for money to clear the bill. Once families return to redeem their child, the hospital bill has increased again and families still cannot take their child home. The parents felt “sad, powerless, depressed, guilty and ashamed” that they were not allowed to take their son home after discharge. The hospital felt like a “prison” and its policy “unfair.” The father expressed his concern that some parents are even forced to abandon their child in hospital. The boys’ parents became desperate. Despite his young age their son realized that he was “detained.” The boy was very worried that his parents would abandon him in hospital and frequently cried over it. Two and-a-half months after admission to MTRH, the parents were informed by a doctor that they could apply for NHIF.

Meanwhile the grandparents, relatives, and villagers believed that the boy was bewitched. They mentioned that time and money were being wasted by visiting the hospital. They believed cancer was not curable. The parents were strongly advised to stop going to MTRH and seek alternative treatment. When the parents continued treatment, the family was isolated and cut off from resources of the farming land. More financial struggles and conflicts evolved.

After 5 months of treatment, the parents took their son home. The parents had sold their two cows and three sheep to cover the hospital bill. A quarter of the hospital bill was waived. No one from the family or village offered financial support. NHIF was not operational yet. The father rendered his national identification card and title deed as surety. The boy was happy to be home, he looked healthy again and started going to school. The tremendous social pressure made the parents not return to MTRH for treatment continuation.

However, after 5 months, the boy started to have nose bleeds again. The parents took him immediately to MTRH. This time the parents were determined to complete treatment. By now, NHIF was operational and covered the hospital bill. The boy himself was very anxious, each time he was taken to MTRH because he feared he would be “detained” again.

The boy continued chemotherapeutic regimen at MTRH until he died at the age of 5 years. After his burial, his parents moved over100 km away from their native land. The parents cannot live in their community because of everything that transpired in the process of their child

receiving treatment. The parents live in a mud house without electricity. Their source of water is a river stream. Up to now, the parents still have debts at the hospital.

DISCUSSION

Our study showed that the relative risk for abandonment of cancer treatment relative to event-free survival was less favorable in children from families without NHIF when compared to children from families with NHIF. Abandonment of childhood cancer treatment was the most important reason for treatment failure in MTRH. These findings suggest that the outcomes of childhood cancer treatment may be improved substantially by interventions that help to improve adherence, prevent abandonment and ameliorate access to NHIF. Costs for NHIF are low, even for the 50% of Kenyans living below poverty line [35], and benefits are high. It is thus very important to inform all parents immediately at diagnosis about the possibility of obtaining NHIF. It would be advantageous to actively guide parents with the application process. Parents of our case report were informed about NHIF after 2.5 months. This is too late. By the time that their NHIF became operational, the financial difficulties and social pressure had escalated to such an extent, that the child's parents had already abandoned treatment.

A limitation of this study was the large number of medical records with missing data. Many records were in poor condition. Important information was often not categorized or not documented at all. Record keeping requires rigorous improvement. Although the imputation models considered in the statistical analysis all yielded the same conclusions, the results should therefore be interpreted with care. Most importantly, the data available for imputing the missing values did not include possibly relevant predictors for obtaining NHIF, such as socio-economic status or income.

The hospital retention and waiving procedure in public hospitals may have various implications for children and families: (1) if parents escape with their child, the hospital bill must be paid by security guard, social worker, and sometimes nurse. Punishing these employees may result in more restrictive and harsh attitudes toward parents. (2) Social workers must find out if the parents or their relatives can pay the hospital bill. The pressure social workers put on families can be significant. Parents may be forced to sell livestock, pieces of land, other possessions, or have their relatives pay for it. The sick child then becomes a significant financial burden for the family. Relatives may even suggest getting rid of

the child. (3) Parents may become desperate: they cannot leave the hospital with their child and every extra day in hospital adds to the medical bill and daily wages are lost. Parents may live in a remote area where they have other children who also need to be taken care of. Parents see other children die on ward and may conclude that their child's condition is incurable. In despair parents may decide that theonly way out is to abandon their sick child in hospital, either temporarily or permanently. (4) In the family or village community, it may not be accepted that parents either abandoned their child in hospital or continue treatment against their advice. Subsequently parents may experience social isolation or excommunication.

The hospital retention and waiving procedure may contribute to non-adherence with treatment in various ways: (1) In Kenya, it is public knowledge that children are retained in public hospitals if parents cannot pay hospital bill [8–10]. This may frighten many poor families and encourage them to use alternative treatments, like herbal medicine or witchcraft, instead of bringing children to a public hospital. This may partly explain the lower reported than anticipated incidence of childhood malignancies in the service area of MTRH. This may also result in delays in health-seeking behavior and subsequent late presentations of advanced stages of disease [38,42]. (2) For poor families who eventually do come with their sick child to a public hospital, the hospital retention and waiving procedure may cause them to distrust healthcare providers. Parents and patients may adhere less with prescribed treatment if they have no sympathy and respect for their healthcare providers [43–45]. (3) Because there are no written, clear, transparent criteria, rules, and regulations involved in the waiving process, parents and patients feel powerless. The less people sense that they are in control the worse they may adhere to treatment [43,46–48]. (4) Forced separation from their sick child and exposure to the waiving procedure may be such a traumatizing experience to parents and child that they decide it is better to abandon treatment than to return to hospital to complete treatment.

In low-income countries, social workers could play a key role in the medical team preventing treatment abandonment. However, in Kenya, limited to their role of guardian over payment of hospital fees, social workers' most valuable contribution in the direction of preventing treatment abandonment is lost.

Future studies need to explore the nature of hospital retention and waiving procedure in more detail. Insight into families' experiences, the number of retained children, and the length of retention is required [8]. Currently, we are investigating other contributors to poor cancer survival at MTRH, including health seeking behavior, knowledge, and attitudes towards childhood cancer of both parents as well as healthcare providers.

On the basis of this retrospective study and case report, we recommend the following: (1) The nature of waiving procedure should change. This procedure allows children to become the victims of a financial conflict between hospital and their parents. Retention of patients in public hospitals is a violation of UN Human Rights Declaration ratified by Kenyan Parliament in 1963 and must stop [49,50]. New legislation should make it illegal to refuse to release patients who cannot pay their medical bills [33]. (2) Access to NHIF should improve at two levels: (a) At a government level, the Kenyan population needs to be actively encouraged or obliged to enroll in NHIF. The application process should be accelerated. (b) At hospital level, all parents should be informed immediately at diagnosis, both verbally and in writing, about the benefits of NHIF. The application process needs to be actively guided by designated healthcare providers. These measures most likely will increase adherence, reduce abandonment, and improve children's survival of cancer.

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CHAPTER 5

TWO OVERLOOKED CONTRIBUTORS TO ABANDONMENT OF CHILDHOOD CANCER TREATMENT IN KENYA: PARENTS' SOCIAL NETWORK AND EXPERIENCES WITH HOSPITAL RETENTION POLICIES[§]

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ABSTRACT

***Background**: The principal reason for childhood cancer treatment failure in low-income countries is treatment abandonment, the most severe form of non-adherence. Two often neglected factors that may contribute to treatment abandonment are as follows: (a) lack of information and guidance by doctors, along with the negative beliefs of family and friends advising parents, which contributes to misconceptions regarding cancer and its treatment, and (b) a widespread policy in public hospitals by which children are retained after doctor's discharge until medical bills are settled.*

***Objective**: This study explored parents' experiences with hospital retention policies in a Kenyan academic hospital and the impact of attitudes of family and friends on parents' decisions about continuing cancer treatment for their child.*

***Methods**: Home visits were conducted to interview parents of childhood cancer patients who had been diagnosed between 2007 and 2009 and who had abandoned cancer treatment.*

***Results**: Retrospective chart review revealed 98 children diagnosed between 2007 and 2009 whose parents had made the decisions to abandon treatment. During 2011–2012, 53 families (54%) could be reached, and 46 (87%) of these agreed to be interviewed. Parents reported the attitudes of community members (grandparents, relatives, friends, villagers, and church members); 61% believed that the child had been bewitched by some individual, and 74%advised parents to seek alternative treatment or advised them to stop medical treatment (54%). Parents also reported that they were influenced by discussions with other parents who had a child being treated, including that their child's life was in God's hands (87%), the trauma to the child and family of forced hospital stays (84%), the importance of completing treatment (81%), the financial burden of treatment (77%), and the incurability of cancer (74%). These discussions influenced their perceptions of cancer treatment and its usefulness (65%). Thirty-six families (78%) had no health insurance, and 19 of these parents (53%) could not pay their medical bills and were not allowed to take their child home when treatment ended. Parents reported feelings of desperation (95%), powerlessness (95%), and sadness (84%) and that their child has been imprisoned (80%), during the period of retention. The majority of parents (87%) felt that hospital retention of children must cease.*

***Conclusions**: The attitudes and beliefs of parents of children with cancer are impacted by those close to them and their community and may influence their perceptions of cancer treatment and decisions to stop treatment. Hospital retention policies are highly distressing for parents and may contribute to both treatment delays and treatment abandonment. These factors jeopardize treatment outcomes for young patients and require attention and modification.*

INTRODUCTION

The vast majority of children with cancer live in low income countries and have little chance of survival [1,2]. A principal reason for treatment failure in these countries may be nonadherence to recommended therapies. Nonadherence, which forms a continuum from sporadic lapses to total withdrawal or abandonment, can be influenced by both the characteristics of a child, their parents, and their disease and treatment, as well as broader hospital policies and health-care provider attitudes. Treatment abandonment, defined as the failure to initiate or sustain treatment during four or more successive weeks, is the most severe form of nonadherence and is ubiquitous throughout these regions [1–5].

The Moi Teaching and Referral Hospital (MTRH) in Kenya serves as a prime example of this critical issue. Fifty-four percent of childhood cancer patients abandon treatment and thus jeopardize treatment outcomes [6]. In recent qualitative research evaluating families' experiences in this setting, we identified two often overlooked factors that may play an important role in families' decision to abandon cancer treatment at MTRH. First, a lack of information and guidance by doctors may contribute to misconceptions held by parents of childhood cancer patients. These misconceptions may stem from beliefs and attitudes of those surrounding parents (family, community members at home, and other parents on the ward) and adversely impact parents' decisions regarding their child's treatment (results from unpublished study). Second, widespread policies that direct public hospitals to retain children after their doctor's discharge until their parents pay their medical bills [6] sometimes result in patients being retained for months [7–9]. Hospital retention can be traumatic for both parents and children and thus may prompt parents to abandon their child's treatment in order to avoid such a scenario [6–9].

Various studies in low-income countries illustrate that doctors treating children with cancer provide insufficient information and guidance to poor families [4,10–12]. In the absence of clear evidence-based information, the influence of a families' social network, both inside and outside of the hospital, becomes increasingly important in parents' treatment decisions. For instance, 87% of parents whose child received treatment at MTRH stated that they would not have understood their child's disease and the treatment required if they had not talked with other parents on the ward (results from unpublished study). If parents rely on each other for information, these discussions may affect not only their understanding of the disease but also their level of adherence to their child's treatment.

Likewise, when guidance and support from medical staff is lacking, those in the parents' home community may also be significant in guiding attitudes toward treatment.

The retention of either living patients or bodies of deceased patients over unpaid medical bills is a critical issue and has been reported in numerous countries in addition to Kenya [7,13–21]. The current mean retention period of children treated for malignancies at MTRH is 5weeks (results from unpublished study). Forced stays in the hospital due to retention may not only be traumatizing for the children and families involved [6–9] but also further corrodes potential treatment adherence and increases likelihood that children will not be brought back after a period of forced retention.

Treatment abandonment is thus an important contributor to the poor outcomes noted in the treatment of childhood cancer in low-income countries. Misconceptions regarding treatment and hospital retention policies may detrimentally affect the well-being of patients and their families and possess consequences for treatment adherence and ultimately abandonment.

METHODS

Setting

Kenya is a low-income country, and 50% of its population lives below the poverty line [22]. Our study was conducted at MTRH, a tertiary care referral hospital. MTRH is the only hospital in Western Kenya providing curative childhood cancer treatment. Although an estimated 700 childhood cancer patients younger than 15 years are expected in the service area of MTRH, only 110 children are diagnosed with a malignancy per annum, suggesting that many are not coming for treatment [23–25]. The pediatric oncology ward contains 12 beds supervised by one to two pediatricians. Treatment options are limited to chemotherapy and surgery. Radiotherapy is not available. In Kenya, the costs to enroll in national health insurance are low (1.4 Euro per month covers inpatient service for the whole family) and affordable for the poor [26]. Despite its affordability however, less than 10% of Kenyan citizens have health insurance because of lack of information, complexity of applications, and poverty, which demands funds be directed to immediate needs [27,28].

Hospital Retention Policies

If doctors discharge a patient from the hospital and their family cannot pay the medical bill, the parents are not allowed to take their child home. The child is retained in the hospital until the parents can cover the medical bill or until their medical bill is waived, which is a procedure not readily made available [11–13]. For every additional day that the child is retained in the hospital, further charges are added to the bill. The children may be left alone as parents cannot easily visit because of the need to seek funds from family and friends to pay their bill. To enforce this policy, security guards are placed at an iron gate at the entrance of the pediatric ward, thus preventing parents from leaving with their child before their medical bills are settled. In cases where parents do escape with their child, the medical bill will be demanded to be paid by the security guard, social worker, and sometimes by the nurse who took care of the child on the ward [6].

Waiving Procedure

Procedures exist for families who have problems paying for their child's treatment to seek partial or complete payment forgiveness [7–9]; however, written procedures and guidelines do not exist. Social workers assemble information on the families' financial situation and submit it to a waiver committee that comprised the hospital's legal and security officers. This procedure by which social workers, patients, and their families may apply is not made widely known, and there are no transparent rules or regulations that govern committee decisions [6].

Study Design

This exploratory, descriptive study used home-based, informant interviews to explore the influence of parents' social network on their decisions about treatment and their experiences with the hospital retention of their children. These interviews were conducted with parents of children who had been diagnosed with a malignancy at MTRH between January 2007 and January 2009, who subsequently abandoned treatment, and whose whereabouts could be determined. These investigations were part of a more extensive research study on abandonment of childhood cancer treatment in Western Kenya [29].

Home visits were made between December 2011 and August 2012 by an independent experienced interviewer and assistant. Parents' contact information (addresses and phone numbers) was extracted from medical records, and contact was made by phone or through the assistance of

the regional chief (usually an older wise man with high status and the recognized leader of a village or several villages).

The interviews utilized a semi-structured questionnaire and were administered orally in Kiswahili. Most questions were evaluated by parents on two-point, three-point, or four-point rating scales. These questions focused on the parents' reaction to their child's cancer, and the reactions of their family members, friends, villagers, and church members, as well as the information they recalled obtaining from other parents at the hospital, and their experiences with hospital retention polices and the fee waiver procedure. An open-ended question assessed the parental perspectives on hospital retention policies. A panel of doctors and psychologists designed the questionnaire, which was consecutively pilot tested for its content, clarity, and cultural sensitivities with five families who had abandoned treatment for their child. The questionnaire is a modification of one used by the authors in Indonesia [3]. Participants were assured of anonymity and confidentiality, and informed consent was obtained. The Institutional Research and Ethics Committee of MTRH approved the study.

Data Analysis

SPSS (IBM Corporation, Armonk, NY, USA) was used to conduct data management and analysis. For each variable, frequency distributions, median, means, and standard deviations were calculated. Differences in socio-demographic and clinical characteristics between respondents and non-respondents were compared using chi-square, Fisher's exact, and t-tests. Fisher's exact test for variables with over two categories was executed in R version 2.15.0.

RESULTS

Patient and Parent Characteristics

At MTRH, 222 children were newly diagnosed with a malignancy between January 2007 and January 2009. Treatment outcomes were recorded in the medical records of 180 children. Among these 180 cases with recorded outcomes, 98 children (54%) had abandoned treatment [6]. Families of 53 children (54%) were contacted between December 2011 and August 2012.

Families of 34 children (64%) could be reached by phone and families of 19 children (36%) through the assistance of the regional chief. Families of 45 children could not be contacted because contact information was missing in their medical records. Of the 53 contacted families, 46 (87%)

consented to participate in the study. Parents declining consent noted that their children had passed away and reminiscing was too painful. No significant differences existed in age, gender, or type of cancer between the group of children whose caretakers could or could not be contacted. The time span between abandonment and when the home visit occurred ranged from 25 to 64 months (median 44 months).

The respondents included the following caretakers: both parents (35%), mothers (33%), fathers (20%), siblings (7%), grandmother (2%), both uncle and aunt (2%), and uncle (2%). All families had a Christian religious background. Tribal origin was Kalenjin (48%), Luhya (26%), Luo (11%), and others (15%). The distance between the families' residence and MTRH was as follows: <50 km (22%), 50–100 km (30%), and >100 km (48%).

The majority of the 46 children were male (72%). Patients' age range at diagnosis was 0–18 years, with a mean of 9.2 years (SD = 5.0) and median 9 years. Cancer diagnoses were hematological (63%), composed of non-Hodgkin lymphoma (52%) and acute lymphoblastic leukemia (28%). The remainder consisted of solid tumors (22%), rare tumors (11%), and unconfirmed tumors (4%).During the home visits, we found that 80% of the children had died [29].

SOCIAL NETWORK

Nuclear Family

The marital status of parents at the time of interview was as follows: married (70%), widowed (15%), separated (7%), divorced (2%), and single mother (4%). Of the married couples, husbands had one wife (81%), two wives (16%), or three wives (3%). Mothers of children with cancer were either the first wife (97%) or the second wife (3%). Marital problems caused by the child's disease were experienced by 25% of couples, and 3% divorced because of these marital problems. Several parents reported that their spouses believed that the child was bewitched (12%), and they advised stopping treatment (9%) and consulting a traditional healer (21%). Witchcraft is surrounded by secrecy and taboos [30,31]. In this context, it implies that a malicious magic user or witch had put a curse or spell on the child and caused the development of cancer. The witch is either a person close to the family or consulted by a person closer to the family to impose the curse. It is believed that the family must attend a witch doctor to cure the child. The witch doctor subsequently goes into a trance to make contact with ancestors, who will point out the

person who was responsible for bewitching the child. The witch doctor then prescribes a remedy to rid the child from the bewitching spirit.

Community at Home

All parents reported receiving social support from their home community, including grandparents, relatives, friends, villagers, and church members. However, this social support did not necessarily mean support for their decision to seeking conventional cancer treatment for their child. Many parents reported that community members believed that their child was bewitched (61%), advised them to seek alternative treatment (74%), or advised them to stop attending MTRH (54%). Seventeen percent of parents reported that their family had been socially isolated after their child had been diagnosed with cancer. This isolation included, for instance, that families were not spoken to, ignored, excluded from communal activities, and cut off from resources of the farming land. Out of fear for the reaction of the community, 20% of families chose not to disclose their child's cancer. Table 1illustrates the reaction to child's cancer subdivided by various community members at home.

Despite this, the community of family and friends were a frequent source of financial support for parents. Most parents reported receiving financial support to pay for the medical bills from the following: friends (59%), relatives (54%), religious community (50%), village community (48%), and grandparents (37%). In this setting, hospital staff had often asked relatives to pay for medical bills (21%). A house visit to check the families' financial situation was sometimes made by a social worker and security guard from the hospital (5%). In addition, community members would also assist with childcare needs. During periods of hospitalization, the patients' siblings were taken care of primarily by spouses (74%), in addition to grandparents (14%), relatives (14%), villagers (7%), or a housekeeper (2%). A minority (11%) of families reported that siblings took care of themselves.

Table 1. Reaction of community members at home to the child's cancer according to parents (n = 46)

Reaction:	Spouse* (n=34)	Grand-parents** (n=28)	Relatives*** (n=42)	Friends*** (n=41)	Village community*** (n=40)	Religious community*** (n=40)
Gives social support	97%	93%	86%	98%	98%	98%
Acceptance	97%	93%	83%	95%	95%	95%
Left / isolate the family	3%	7%	10%	0%	5%	0%
Disappointing	0%	4%	12%	0%	5%	0%
Believes disease is caused by inheritance	41%	18%	48%	39%	45%	25%
Believes child is bewitched	12%	11%	36%	41%	50%	3%
Advises to seek alternative treatment	21%	25%	38%	63%	63%	18%
Advises not to attend public hospital	9%	11%	19%	29%	38%	10%

* 12 parents had no spouse

** grandparents of18 children had deceased

*** parents did not disclose their child's cancer to relatives (n=4), friends (n=5), village community (n=6) and religious community (n=6)

Other Parents on the Ward

Many parents recalled that they had shared their experiences, feelings, and beliefs with parents of other children with cancer when their child was hospitalized (67%). Caretakers reported that other parents offered emotional support (97%) and that these interactions became 'a world of its own inside hospital walls' and one that was 'out of sight from doctors'. Table 2 illustrates the topics that parents discussed together. The majority of parents interviewed reported that these discussions with other parents influenced their perception of the utility of their child's cancer treatment (65%).

Table 2. Topics discussed with other parents on the ward according to parents (n = 31)

Topics	
The life of your child is in God's hands	27 (87%)
Forced stay in hospital and separation from family is traumatizing	26 (84%)
It is important to complete the whole treatment	25 (81%)
The financial burden of treatment is too much	24 (77%)
Cancer is not curable	23 (74%)
Hospital procedure to waive medical bill is traumatizing	21 (68%)
Surgery spreads cancer	20 (65%)
All children with cancer die	19 (61%)
Child is traumatized with medical procedures	18 (58%)
Feelings of guilt toward siblings	18 (58%)
The health of your child is beyond doctor's control	15 (48%)
It is better to seek alternative treatment	15 (48%)
Children should not suffer from such severe side-effects	10 (32%)
Children should live a normal life or die in peace at home	10 (32%)
If your child appears healthy again, you can stop treatment	7 (23%)
Cancer treatment at public hospital kills your child	6 (19%)
Dissatisfaction with health-care providers	3 (10%)

HOSPITAL RETENTION

Parental Experiences

Before coming to MTRH, 10 families (22%) had health insurance. In these cases, health insurance covered their medical bills, and none of these children were retained in the hospital. The majority of families (78%) however did not have health insurance. After their children had been discharged from the hospital by doctors' orders, parents of 19 children (53%) could not pay the medical bills owed and were not allowed to take their child home.During hospital retention, cancer treatment was continued according to the prescribed treatment protocol in 79% of cases. Hospital retention ranged between 2 and 21 days, with mean 8.4 days (SD = 5.4 days) and median 7 days. Parents of one child reported that they were not allowed to take the body of their child home after the child had died at MTRH, because medical bills were not paid yet. Several parents described the hospital retention policy as particularly painful because it deprived parents of the opportunity to give their children a dignified funeral and burial in the soil where relatives and ancestors were buried.

Waiving Procedure

The possibility of medical bills being waived was communicated by health-care providers to 63% of families whose children were retained. Of these families, the majority (75%) received a partial waiver, whereas the others received complete waivers. The remaining 37% of families with retained children reported that they had not been informed of the possibility of medical costs being waived. These families indicated that, in retrospect, they would have wanted to be informed of this possibility and were unsure why they had not been told. Ultimately, 15 families had to render their national identity card as collateral in order to take their child home; all these families had to first pay part of the medical bill themselves. In Kenya, national identity cards are the primary form of legal identification and are mandatory for all citizens older than 17 years. National identity cards are required, for instance, for employment, to open a bank account, to acquire a driving license, to transact mobile phone banking, to vote during elections, and to register a business [32].

Child Left Alone

When children were retained in the hospital, 53% of parents reported that they had to leave their child alone inside the hospital because the parents needed to search for money, go to work, or take care of siblings left at home. Retained children were then either accompanied by grandparents, siblings, and other relatives (60%), or completely left alone inside the hospital (40%).

Parental Feelings

Table 3 illustrates parental feelings during the hospital retention of their children. Most commonly reported feelings were as follows: desperation (95%), powerlessness (95%), sadness (84%), and perceiving the hospital as like a prison (80%). For some (16%), hospital retention policies made them wish that they had never come to MTRH with their child.

Table 3. Parental feelings during hospital retention of their children (n = 19)

Parental feelings	
Desperate	18 (95%)
Powerless	18 (95%)
Sad	16 (84%)
Imprisoned	15 (80%)
Depressed	13 (68%)
Alone	12 (63%)
Ashamed	8 (42%)
Unfair	8 (42%)
Guilty	7 (37%)
Afraid	6 (32%)
Fine	6 (32%)
Good	3 (16%)
Relaxed	3 (16%)
Happy	2 (11%)
Crying	1 (5%)
Indifferent	1 (5%)

Prior Awareness of Hospital Retention Policies

Among all 46 families interviewed, 33% had heard about hospital retention policies in public hospitals before they came to MTRH. Twenty-seven percent of those who had heard of the retention polices reported that this caused them to delay coming to MTRH.

Parental Criticism of Hospital Retention Policies

The majority of parents (n = 40, 87%) felt that retention of children in public hospitals needed to cease and provided multiple reasons for this belief (Table 4). Only six families (13%) believed that hospital retention policies should continue, of which four had had their child retained. These parents acknowledged that retention of patients was a problem but believed that the hospital needed money to provide care. They felt that the alternative would be that no children would receive cancer treatment, which was an even greater problem.

Table 4. Parental criticism of hospital retention policies: reasons why hospital retention of children after doctor's discharge must stop according to parents (n=40)

Reasons why hospital retention must stop
- Forced hospital stays are unfair and traumatizing to children and their families.
- It is not the fault of parents that they are poor.
- It is not the fault of children that they are sick.
- Medical bills continue to accumulate while families go out searching for money to clear medical bills. When parents come back to pay their balance and take their child home, the total bill has increased again and parents still cannot take their child home.
- Parents become desperate and feel that there is no way out.
- Forced hospital stays stimulate treatment abandonment after their child has been released, which will lead to the child's death due to disease progression or relapse.
- The child may be left behind, alone inside hospital, either temporarily or permanently.
- Separation from their family harms children. In particular, when children are sick, they need the comfort of their parents. Children become depressed due to separation from their family.
- Retained children are exposed to infections inside hospital.
- Protests of community members at home to high treatment costs can lead to social isolation or excommunication.
- Retained children are denied the opportunity to attend school.

DISCUSSION

Widely held misconceptions of cancer, along with widespread hospital policies, may adversely affect the welfare of patients and families in low-income countries and may have implications for consequent treatment adherence and abandonment. In the absence of clear advice from medical providers, parents' attitudes and beliefs regarding treatment may be influenced by members of their community and parents of other children with cancer whom they met in the context of treatment. This study illustrated that families' social network and parental experiences with hospital retention policies may contribute to nonadherence and abandonment of cancer treatment.

Various studies from high-income countries underline that treatment adherence is related to available social support [33–35]. A close family bond, the presence of local help, and the encouragement of others can improve adherence to medical regimens. For example, supportive family members may remind patients to take medication or attend hospital appointments and thus enhance treatment compliance. Emotional support can also reduce distress among parents and consequently their children and thus improve treatment adherence [33–36].

In the current study, we found that all caretakers of children with cancer received social support from community members at home, including spouses, grandparents, relatives, villagers, and church members. However, members of parents' social network did not always encourage adherence to conventional cancer treatment and may have enhanced misconceptions of cancer. For example, many parents reported that community members believed that their child was bewitched and consequently advised them to seek out traditional healers. In fact, half of all parents were strongly advised by community members to stop treatment at MTRH. This illustrates the possible role of public awareness campaigns that are needed to educate people about cancer and that witches and witchcraft do not cause illness, which may in turn reduce the communities' fear of witches and bewitched children and enhance their access to timely curative treatment [29,30]. Booklets about childhood cancer for parents of newly diagnosed children would help them to educate others and reduce the ignorance and social isolation. Communities in Kenya are characterized by a collectivist mentality and typically offer financial support to families in need [37]. Many community members had indeed offered financial support to the family; however, when they then saw no improvement of the child's condition, they concluded that treatment at MTRH was a futile waste of money. Because most Kenyan communities live in great poverty, the family's decision to continue expensive cancer treatment aroused strong negative sentiments among community members. We learned that some families had decided not to disclose their child's condition to various community members out of fear of being stigmatized, isolated, or excommunicated.

Previous research in low-income countries illustrates that doctors' delivery of information and guidance to poor families is meager [4,10–12]. In this vacuum of support and education, the role of a social network can become increasingly significant to families, both outside and inside the hospital. For example, 87% of caretakers of children treated for cancer in MTRH mentioned that they would not have understood cancer and its treatment if they had not been able to consult other parents on the ward (results from unpublished study). If parents depend on one another for information, it is essential to know what parents discuss and how this may impact their decision to adhere to or abandon treatment. Our study illustrated that although they learned more about cancer and felt supported by others, some discussion topics may have undermined treatment adherence, such as fostering beliefs that their child's life was in God's hands alone, that the financial burden of treatment was too great, and that the cancer was incurable. Optimistic attitudes, a sense of

control, and words of hope are important in increasing families' motivation for treatment, whereas feelings of helplessness, powerlessness, and despair undermine adherence and may ultimately lead to abandonment [6,38].

This study showed that half of all families without health insurance faced retention of their children because of hospital policy. About one-third of these families were not informed by hospital staff that a waiver could be sought for their medical bills. The nature of hospital retention may contribute to nonadherence to treatment ina number of ways. First, hospital retention policies may scare and prevent poor families from coming to public hospitals at all, thereby contributing to the lower-than expected childhood cancer incidence in the service area of MTRH [23–25]. In addition, parents may be reluctant to bring children in after a period of retention because of fear of it happening again. Critically, one-third of families who knew about hospital retention policies beforehand reported delaying in coming to MTRH because they feared forced separation from their children. Hospital retention was associated with feelings of powerlessness among parents affected. The fact that the process by which medical bill waiver requests are submitted and adjudicated lacks written guidelines or criteria, and transparency further exacerbates this sense of powerlessness among families. Evidence suggests that the less control families may feel they have, the less they may adhere to treatment recommendations [33,39]. Finally, hospital retention policies were perceived as a traumatizing experience. Parents described feelings of despair and sadness and that their child's hospital retention felt like a form of imprisonment. The forced separation from their sick child may be sufficiently traumatic for parents and children that they decide it is better to abandon treatment than to return to the hospital to complete treatment. This is particularly worrying in the context of pediatric oncology care, as many types of cancer can be cured despite the limited resources and lack of available radiotherapy.

When parents were asked during the interview if hospital retention policies should stop, the vast majority of parents strongly condemned 'the imprisonment of innocent children'. Parents were able to note numerous reasons why hospital retention policies should cease. This study shows their willingness to report their experience and suggests the need for international pediatric oncology organizations to raise awareness in the global community regarding hospital retention policies in low-income countries and their negative impact on families and patients treatment adherence.

Although health-insurance coverage is affordable and covers the cost of care, only 22% of families had health insurance. This is quite remarkable as insurance costs in Kenya are low even by Kenyan standards and benefits are high [25–27]. Greater efforts are needed on a national level to raise awareness and increase enrollment in health-insurance coverage and in turn reduce financially related distress. Kenyan residents should be actively encouraged or obliged to enroll in health insurance, whereas basic health insurance should be provided to citizens who cannot afford national health insurance. A better organized, taxpayer-funded system could enable equal access to health-care services for all Kenyans [6].

Our study has several limitations. Tracing families was particularly difficult because the study was conducted several years after the children had been treated for cancer. Many medical records were completely missing, whereas medical records that were located frequently lacked contact information. Even if contact information was available, the information was often not up to date as families had moved or changed phone numbers. As a consequence, we could only reach half of all intended families. In addition, some families declined participation, which may also have influenced our study results.

On the basis of this exploratory study, and despite these limitations, we recommend that the following steps should be taken in the interest of caring for children with cancer. First, although social networks often provide important tangible support (e.g., child care), misconceptions regarding cancer causes and treatment need to be addressed so that families are encouraged to adhere to potentially life-saving treatment. Our study identified several potential mechanisms that could facilitate this transition: providing a structure to the social network inside the hospital and organizing parental supportive meetings to be supervised by a doctor and psychological counselor to ensure that accurate information is disseminated. This will create an outlet for parents to express needs and share experiences in a manner that is constructive instead of destructive. It will also create an opportunity for health-care providers to improve their delivery of information and guidance and clarify any sources of misunderstanding.

Second, in regard to community-based social networks, we believe it would be advisable to distribute educational materials that parents can show community members at home. For instance, an information booklet about cancer, its curability, and the type of treatment required would not

only provide parents with a better understanding of their child's disease but also aid parents in their discussions with community members. This information could also serve to challenge widely held beliefs regarding cancer and witchcraft and reduce the stigma and isolation that often result. Doctors are advised to proactively ask parents about their social network at home and its contribution to their perceptions of treatment and its importance. If necessary, doctors can invite community members to come and discuss their concerns inside the hospital.

On a national level, hospital retention policies in public hospitals violate basic principles of international law and must end. The Kenyan Parliament should respect its ratification of the United Nations Human Rights Declaration in 1963 [40]. Legislation needs to be introduced that makes it illegal to hold patients who are unable to pay their medical bills [20]. These measures would go far in ameliorating issues of treatment adherence, decrease abandonment, and ultimately enhance the survival outcomes of children diagnosed with cancer.

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CHAPTER 6

PARENTAL EXPERIENCES OF CHILDHOOD CANCER TREATMENT IN KENYA[**]

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ABSTRACT

Purpose: *Our study explores socio-economic, treatment-related and psychological experiences of parents during cancer treatment of their children at an academic hospital in Kenya.*

Methods: *This cross-sectional study used semi-structured questionnaires. Parents whose children came for cancer treatment consecutively between November 2012 and April 2013 were interviewed.*

Results: *Between 2012 and 2013, 115 oncology patients attended the hospital and 75 families (response rate 65%) were interviewed. Cancer treatment resulted in financial difficulties (89%). More information about cancer and treatment was required (88%). More contact with doctors was needed (83%). At diagnosis, cancer was perceived as curable (63%). However, parents were told by health-care providers that most children with cancer die (49%). Parents had difficulties with understanding doctors' vocabulary (48%). Common reasons to miss hospital appointments were: travel costs (52%) and hospital costs (28%). Parents (95%) used complementary alternative treatment (CAM) for their children. Health-care providers told parents not to use CAM (49%). Parents had not discussed their CAM use with doctors (71%). Community members isolated families because their child had cancer (25%), believed that child was bewitched (57%), advised to use CAM (61%), and stop conventional treatment (45%).Some families (15%) never disclosed the child's illness to community members. Parents shared experiences with other parents at the ward (97%) and would otherwise not understand the disease and its treatment (87%).*

Conclusions: *Parents suffer financial hardships and are dissatisfied with doctors' communication regarding their children's condition. CAM is very commonly used. Doctors need to improve their communication skills and discuss CAM more openly. Cancer programs should include more support for parents: financial assistance, a facility where parents and children can stay during the course of therapy, and parent support groups.*

Abbreviations: *MTRH - Moi Teaching and Referral Hospital; CAM - Complementary Alternative Treatment*

INTRODUCTION

The burden of childhood cancer is disproportionately greater in low-income countries as compared to high-income countries.More than 90% of deaths among children aged below 15 years worldwide occur in low-income countries. (1-5)

Africa is greatly underserved in terms of providing care for pediatric oncology patients. More than 80% of the children with cancer die without access to adequate treatment. This is mainly due to inadequate healthcare budgets, scarce diagnostic facilities and paucity of appropriately trained personnel. Hospitals generally serve a large number of pediatric oncology patients in proportion to the doctors available. In addition, doctors do not prioritize communication with patients and their families. (6,7) As a result families may not fully understand their child's illness and the need to adhere with cancer treatment. Abandonment of cancer treatment, the most severe type of non-adherence, is the most common reason for cancer treatment failure in Africa and other low-income countries. (3,6)

In low- and high-income countries childhood cancer has devastating effects on both the child and family. Having a child with cancer is one of the most distressing life experiences for families. Parents experience numerous socio-economic, treatment-related and psychological challenges. Families are unable to resume a normal life during the treatment of their children. (8-12).

There is a paucity of information regarding the effects of childhood cancer treatment on parents, especially in Africa. This study explores socio-economic, treatment-related and psychological experiences of parents during cancer treatment of their children at an academic hospital in Kenya.

METHODS

Setting

This study was conducted at Moi Teaching and Referral Hospital (MTRH) which is located in Eldoret, western Kenya. It is the second largest public tertiary hospital in the country with a catchment area of 18 million people.About 110 new pediatric-oncology patients are seen in MTRH per year. (13-15)Patients are taken care of in an inpatient unit within pediatric wards and an outpatient clinic that runs once per week. The pediatric wards include 72 beds, of which 12 beds are reserved for cancer patients

often with more than 100% occupancy. Pediatric-oncology ward is supervised by one to two pediatricians.

Study Design

This cross-sectional study was conducted using a semi-structured questionnaire, which focused on assessing socio-economic, treatment-related and psychological experiences of parents during the treatment of their child with cancer. All consecutive parents of childhood cancer patients who attended MTRH between November 2012 andApril 2013 were requested to be interviewed. Parents were interviewed by two independent interviewers. The questionnaire contained statements that could be answered on two, three or four-point rating scales. There was an English and Kiswahili version of the questionnaire. A pilot-test was done by interviewing 5 parents of childhood cancer patients to detect questions that were unclear or too complicated. Small adaptations were made based on the pilot-test. The interviews were held in a private area, where only the interviewers and parents were present. Each of the interviews took about 30 minutes. Confidentiality was maintained. The questionnaire was approved by the Institutional Research and Ethics Committee of MTRH.

Data Analysis

Frequency distributions, median, means and standard deviations were calculated. Differences in socio-demographic and clinical characteristics between respondents and non-respondents were compared using chi-square and Fisher's Exact tests. Fisher's Exact tests for variables with more than two categories were performed in R version 2.15.0. Data management and analysis were performed by using SPSS for Windows version 20.0.

RESULTS

Patient Characteristics

Between November 2012 and April 2013, 115 oncology patients attended MTRH. Parents of 75 children were interviewed (response rate 65%). Parents of 40 patients (35%) were not interviewed for different reasons: parents only briefly attended outpatient clinic (67%), did not give consent (10%), language barrier: parents could not communicate in any of the languages understood by interviewers (8%), patients either deceased (8%) or abandoned treatment (5%) before interview took place, or came to appointments unaccompanied by parents (2%). There were no significant differences in the children's age at diagnosis, genderor type of cancer between respondents (n=75) and non-

respondents (n=40). Table 1 illustrates socio-demographic characteristics of parents of childhood cancer patients (n=75).

Of 75 childhood oncology patients whose parents were interviewed, 43 (57%) were male. Patients were between 0-14 years old at diagnosis. Figure 1 illustrates their distribution of diagnoses. At the time of interviewing, children were at the phase of diagnosis and staging (5%), undergoing treatment (82%) or had completed treatment (13%).

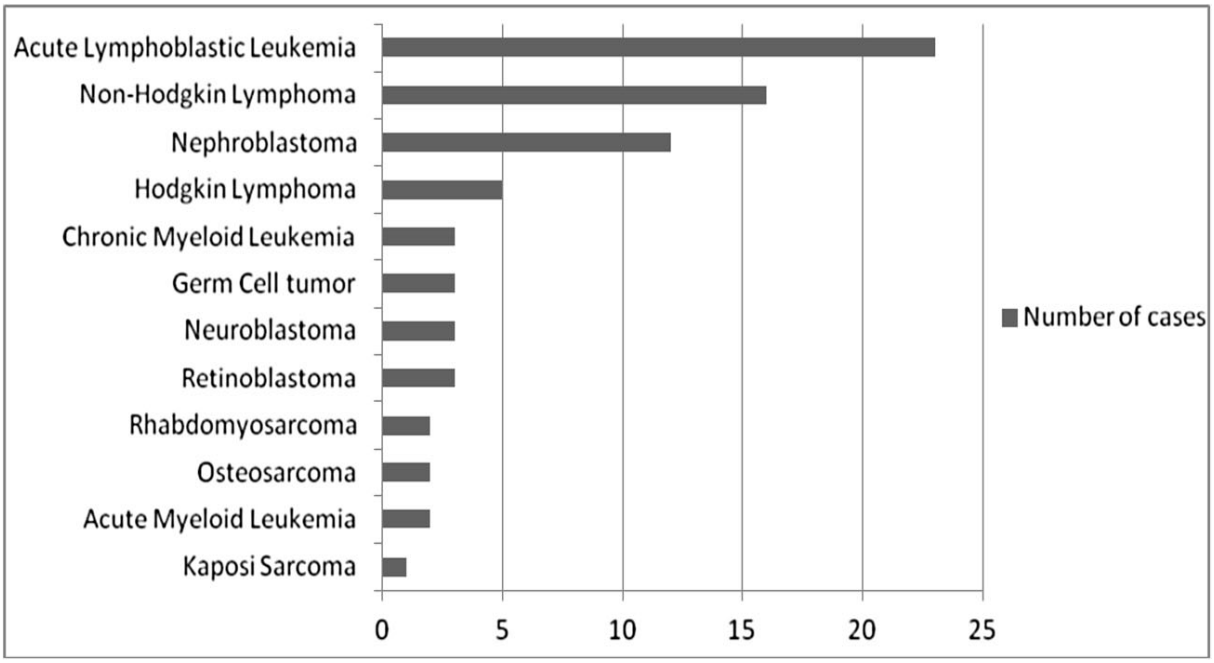

Figure 1. Diagnosis of children whose parents were interviewed. (n=75)

Table 1. Socio-demographic characteristics of parents of childhood cancer patients (n=75).

Socio-demographic characteristics	**%**	**%**
Respondents:		
Mothers		70%
Fathers		15%
Grandparents		5%
Uncles		4%
Aunts		4%
Sibling		1%
Orphanage employee		1%
Marital status		
Married		67%
Widowed		12%
Single		10%
Separated		7%
Divorced		**3%**
Deceased1%		
Parental educational status:	Fathers (n=59)*:	Mothers (n=69)**:
Low (no education, primary school)	45%	61%
Intermediate (high school)	28%	24%
High (university, other tertiary institute)	5%	7%
Parental occupation:	Fathers (n=59)*:	Mothers (n=69)**:
Housewife	0%	35%
Regular job	37%	27%
Farmer	29%	25%
Laborer/irregular job	15%	6%
Unemployed	9%	4%
Student	0%	3%
Family's monthly income (n=65)***:		
<12 USD		5%
12-60 USD		63%
60-100 USD		12%
> 100 USD		7%
Main economic provider:		
Father		48%
Mother		28%
Both parents		15%
Other caregiver		9%
Distance to MTRH:		
< 50 km		13%
50-100 km		23%
> 100 km		64%
Transportation mode to MTRH		
Public transport		83%
Walking and public transport		13%
Private vehicle		3%
Walking		**1%**
Travel time to MTRH:		
< 1 hour		**4%**
1-3 hours		37%
> 3 hours		59%

* Educational level of father was unknown according to the mother in 16 children: 9 fathers had died and 7 had left the family.** Educational level of mother was unknown in 6 children: 2 mothers had died and 4 had left the family. Mothers had low (61%), intermediate (24%) or high education (7%). *** Ten families (13%) could not report their monthly income.

SOCIO-ECONOMIC EXPERIENCES

Financial Situation and Transportation

Most families had no regular income (63%). A total of 64% of families owned land. This land was either taken care of during hospitalization (85%) or neglected (15%). The majority of families reported a decrease in income since the start of treatment (66%). Cancer treatment resulted in financial difficulties (89%) and debts (64%). Financial struggles were perceived as great burden (83%). Parents had to sell valuables (76%), like live-stock (60%), land (9%) or other possessions (23%). Families received financial support from friends (47%), relatives (41%) religious community (36%) or grandparents (29%). Families experienced difficulties in providing food for their child at home (47%). Treatment costs forced families to withhold their child from certain aspects of prescribed treatment (28%). Some families (29%) expected not to be able to complete treatment due to financial problems, and 23% were uncertain about this. Traveling to hospital was considered to be expensive (84%), time consuming (77%) and difficult (45%). Reasons not to attend appointments in hospital were: travel costs (52%), inadequate transport facilities (20%) and distance from clinic (20%).

TREATMENT-RELATED EXPERIENCES

Parental Education and Communication with Doctors

The information at diagnosis about cancer and its treatment was given by: doctor (74%), nurse (11%), counselor (11%), social worker (4%), and another parent at ward (1%). Parents were either aware of the specific diagnosis of their child (74%) or knew that their child had cancer (26%).Parents felt more information about cancer and its treatment was required (88%). More contact with doctors was needed (83%). Parents were told by health-care providers that most children with cancer die (49%) and that their child's fate is in God's hands (56%). Parents had difficulties with understanding doctors' vocabulary (48%) and the information provided (36%). Parents hesitated to ask questions or attention from doctors (51%) because: families did not get a chance to ask questions or attention (58%), doctors seemed too busy (58%), fear that doctors become irritated (42%) and this irritation may harm their child's treatment (32%), doctors had high status (18%). The parents disagreed (86%) or were uncertain (7%) that getting more information about cancer will make them afraid or depressed.

Table 2. Causes of childhood cancer according to parents (n=75); more than one answer was allowed.

Causes of childhood cancer	%
Exposure to chemicals	80
Not known/unclear	67
Food intake	63
Inheritance*	58
Bad luck	40
Supernatural	32
Destiny	23
No cause	20
Curse	13
Witchcraft	8
Conflict	5
Environmental factors	4
Punishment by God	1
Exposure to plastic bags and other plastics	1
Uncleanliness/ lack of hygiene	1
Missing childhood immunization	1
Getting kick in chest	1
Sleeping with open mouth and breathing in dust	1
Same cause as any other disease	1
Contagious	1

* Inheritance in this context does not refer to genes but rather it means parents pass on the disease to their children because of curse that has been subjected to the family by a supernatural being.

Health Beliefs

Parents had some prior knowledge about cancer before the diagnosis of their child was made (75%). At diagnosis cancer was perceived as curable (63%). Table 2 illustrates the causes of childhood cancer according to parents. The use of surgery in cancer may be helpful (85%) and necessary (80%), but is also believed to be frightening (61%), causing death (45%) and spreading cancer (30%). Cancer can be cured according to 88% of parents, 9% were uncertain, and 3% disagreed. The health of their child was beyond doctor's control and determined by luck, fate or God according to 27% of parents, 5% were uncertain and 68% disagreed. Once their child appears healthy again, cancer is cured according to 40% of parents, 13% were uncertain and 47% disagreed. Most children with cancer die according to 55% of parents, 20% were uncertain, and 25% disagreed. Chemotherapy can only cure cancer, if total treatment is completed according to 81% of parents, 14% were uncertain, and 5% disagreed.

Adherence with Hospital Appointments and Medication

Strict patient adherence with prescribed dosage and timing of medication is crucial and improves the chances of survival of the children according to all 75 parents. Table 3 presents reasons for non-adherence with medication administration and hospital appointments according to parents. An accumulation of unused tablets at home was reported by 15% of parents.

Complementary Alternative Treatment

Parents (95%) used complementary alternative treatment (CAM): spiritual or religious help (89%), herbalist (43%), special food intake (9%), and traditional healer (5%). None of the parents reported to have used witchcraft. Table 4 shows the reasons why parents used CAM. Parents believe that doctors have negative perspectives of CAM (75%). Health-care providers told 49% of parents not to use CAM. Families find it difficult to discuss CAM with doctors (88%) and parents had also not discussed their use of CAM with doctors themselves (71%). Parents feared that they would receive less care from doctors if they expressed doubts about the effectiveness of conventional treatment or authority of doctors (25%).

Table 3. Reasons for non-adherence with medication administration (n=71) and hospital appointments (n=75) according to parents of childhood cancer patients; more than one answer was allowed.

Reasons for non-adherence with medication administration (n=71)*:	**(%)**
Financial difficulties of parents	38
Inadequate drugs supply at pharmacy	30
Forgetting	20
Too busy	18
No food available for child	11
Lack of motivation parents	11
Alternative treatment	10
Side-effects	10
Child is in pain	10
Lack of motivation doctors	8
Child looks healthy	7
Lack of knowledge protocol	6
Child refuses drugs	4
Child looks ill	3
Not necessary	1
Reasons for non-adherence with hospital appointments (n=75):	
Travel costs	52
Hospital costs	28
Loss of daily wages	24
Distance to clinic	20
Inadequate transport facilities	20
Retention of child in hospital	15
Hospital procedure to clear hospital bill	15
Not satisfied with provided care	11
Time clinic appointment is inconvenient	11
Forget appointments	9
Going to work	9
Do not see benefit of hospital appointment	8
Nobody to look after other children	8
Too busy	8
Child appears healthy	9
Nobody to look after land	7
Child is in pain	5
Child appears ill	4

*Parents of all 71 children who were either on treatment or had completed treatment.

Table 4. Reasons for using complementary alternative treatment according to parents of childhood cancer patients (n=75); more than one answer was allowed.

Reasons for complementary alternative treatment:	%
Hope for cure	53
Hope for improvement child's condition	47
Helpful	43
Recommended by others	37
Certainty of cure	36
Other patients look healthy after taking it	27
Recommended by parents of other patients	25
Cheap	23
Easy accessible	23
At short distance available	20
No side-effects	13
Child can stay inside the family	13
Child will not be retained in hospital	12
No painful medical procedures	12
No discomfort	11
Fear of surgery in hospital	9
Conventional treatment has no certainty of cure	8
Chemotherapy has side-effects	5

PSYCHOLOGICAL EXPERIENCES

Coping

The emotional state of their child was described as somewhat unhappy (17%), very unhappy (19%), and so unhappy that life was not worthwhile (1%). The parents' own emotional state was described as somewhat unhappy (28%), and very unhappy (7%). The feelings most parents experienced towards the disease of their child were acceptance (100%), optimism (92%) sadness (68%), worrying (65%), preoccupation with the progress of disease (60%), hopelessness (39%), fear (39%), preoccupation with physical functions (39%), preoccupation with fatal return of cancer (33%), depression (21%) and shame (3%). Marital problems caused by disease and treatment of their child were reported by 13% of parents.

Siblings

Sixty-seven parents had more than 1 child. Parents reported to have less time and energy for siblings (79%). Parents were afraid for siblings' well-being (52%). Siblings felt neglected by their parents (45%). Parents said to be overprotective of siblings (36%), and to have feelings of guilt toward siblings (34%). During treatment of their child in hospital siblings were taken care of by: father (30%), older sibling (19%), mother (18%), grandmother (13%), relatives (13%), neighbors (7%), house help (4%),

or orphanage worker (1%). In two families the children were considered to be old enough to take care of themselves (3%).

Social Network

Table 5 illustrates the reaction of social network to child's cancer. Social support from community members was received by almost all parents (96%): spouses, grandparents, relatives, villagers and church members.However, community members isolated families because their child had cancer (25%), believed that the child was bewitched (57%), advised to use alternative treatment (61%), and advised to stop treatment at MTRH (45%).Totally, 15% of families decided not to disclose their child's cancer to community members at home.

Table 5. Reaction of social network to the child's cancer according to parents of childhood cancer patients (n=75)

Reaction:	Spouse* (n=55)	Grand-parents** (n=59)	Relatives*** (n=72)	Friends*** (n=72)	Village community*** (n=71)	Religious community*** (n=67)
Gives social support	91%	81%	72%	72%	59%	87%
Acceptance	91%	81%	83%	83%	83%	87%
Left / isolate the family	4%	3%	14%	17%	14%	6%
Disappointing	15%	17%	26%	28%	18%	10%
Believes disease is caused by inheritance	25%	17%	25%	26%	21%	10%
Believes child is bewitched	16%	17%	33%	39%	34%	13%
Advises to seek alternative treatment	22%	25%	36%	36%	39%	7%
Advises not to attend public hospital	16%	14%	28%	22%	25%	6%

*20 parents had no spouse

** grandparents of 16 children had deceased

Interaction with Other Parents at the Hospital Ward

Parents shared experiences with other parents of children with cancer at the ward (97%) and received emotional support from them (95%). Parents explained they feel they have a close bond with other parents because they face similar difficulties (93%). This emotional support from other parents was described as very important (90%).Experiences shared with other parents were: progress of disease (96%), management of side-effects (88%), adverse effects of disease (88%), and alternative therapies (20%).It was good to learn from the experiences of other

parents, because parents otherwise would not understand the disease and its treatment (87%).Health-care providers were busy and therefore could not provide them with sufficient information, advice or emotional support (53%). However, advice from emotionally close parents was not considered to be more valuable than the opinions of health-care providers (88%).

DISCUSSION

This study reveals that parents of children with cancer in Kenya, Africa undergo a wide variety of socio-economic, treatment-related and psychological experiences. The majority of parents reported financial difficulties (89%) and a reduction in family's income (66%). This results from the fact that parents take time off their jobs to be with their sick child in hospital. Since a big proportion of parents work as casual laborers, any absence from their work place results in loss of day's wages. Among parents of Indonesian children with acute lymphoblastic leukemia, 69% of parents reported a reduction in their income.(11)Despite their financial difficulties, only one-third of Kenyan parents expected not to be able to complete cancer treatment. Potential solutions to financial problems would include lobbying for more government and donor funding which can help cover some of the expenses the parents incur.

Transport to hospital was described as expensive, time consuming and difficult. It was also cited as the most common reason why parents miss hospital appointments. Majority of parents have low social-economic backgrounds and use public transportation which is rather disorganized in Kenya.(16,17) This, coupled with long distances to hospital could explain the reason why transport was described as expensive and time consuming. Some ways of alleviating transport problems would include providing financial support to parents or having a house near the hospital where families could stay in between treatment courses.

Majority of parents (88%) felt that they required more information to understand diagnosis and treatment of their child. In Indonesia, 86% of parents with children with acute lymphoblastic leukemia also felt they needed more information about their child's condition from doctors. Likewise, majority of Kenyan parents (83%) felt that they needed more contact with doctors similar to what was reported in Indonesia (77%).(11) Parents had difficulties approaching doctors to ask them questions regarding their children. This could be due to a combination of the fact that there are relatively few doctors in MTRH and that doctors are regarded as members of higher social status. In Kenya, it is culturally not

accepted to question somebody of a higher status. Parents also had difficulties understanding the language used by doctors. As legacy of British colonization, English is Kenya's' official language. However, English is learnt in school and is hardly the first language for the vast majority of low-educated poor Kenyans. Kenya harbors many different tribes with their own ethnic languages or dialects. Also in our study more than half of parents had low education levels and consequently problems understanding English can be expected. Most of our parents would be more fluent in Kiswahili which is the national language. A minority of Kenyans belongs to high socio-economic strata and use English as means for communication.(18,19) In hospitals doctors communicate among themselves in English. Maybe unintended, the use of English emphasizes the difference in social hierarchy between doctors and families. This will hinder communication further. All these coupled with the fact that health-care providers also use medical terminologies, which are difficult to translate in Kiswahili, makes it difficult for parents to understand. The doctors also spend very minimal time with the patients during daily ward rounds due to the high number of patients. This calls for more training among doctors regarding proper communication skills. Other staff especially nurses and counselors should be given more training about the various childhood cancers so that they are able to provide more information to parents.

At diagnosis most parents (63%) perceived childhood cancer to be curable. However, half of the parents were subsequently informed by health-care providers that children with cancer are likely to die. The latter may be understandable as cancer survival is low at MTRH (20) and health-care providers could have come across many children with cancer who have died, but negative comments are certainly not advisable. Parents were still hopeful of a cure and such pessimism from medical staff may discourage families to adhere with treatment and opt out. At MTRH 54% of children abandon cancer treatment.(20) This will result in poorer cancer survival.

Almost all parents (95%) had used complementary alternative medicine in the course of the illness of their children with the commonest forms being spiritual help and traditional healers. Other studies have reported high rates of use of CAM among children with cancer both in low and high-income countries: Jordan (65%), Turkey (49%), Netherlands (42%), Indonesia (37%) and Germany (35%).(11,21-24) However, different types of CAM are used in Kenya compared to other countries in the world. The majority of the parents in this study report using spiritual help

which could be explained by the fact that most people are deeply religious. Communities living in Kenya still strongly follow their traditional practices and this may explain why many of them seek traditional healers as a way of improving the condition of their children. It is also interesting to note that no parents reported use of witchcraft despite being advised by community members that their children had been bewitched. In most cultures, if an individual is believed to be bewitched, they need to consult a witchdoctor to remove the curse. The witchdoctor blames the illness on a curse from a community member and this is often a person close to those who are seeking his services. One would therefore not publicly admit to have visited a witchdoctor as this means they are blaming somebody in their close social network for the child's cancer.(25,26)

Despite a large number of families using CAM, most parents never discussed its use with doctors (71%). Also in the Netherlands only 33% of parents discussed the issue with doctors.(24)Half of our parents were told not to use CAM by doctors. This means there is a great disconnect between doctors and parents on this subject. Parents have valid reasons to use CAM and it would be helpful if the doctors became more open and discuss the subject with parents. For doctors to do this in a useful manner they will require more knowledge about CAM.

The communal way of living in Kenya is exemplified by the fact that families received financial and social support from the community.(18,19) However, community members believed that the children with cancer were bewitched. The parents were advised to stop treatment at MTRH and seek necessary CAM care. This may imply that the level of knowledge and understanding of childhood cancer in the community is quite low. It also implies that, in contradiction to what is reported in the western world where social support helps to improve adherence with conventional treatment, in Kenya social support may result in non-adherence.(26,27) In Indonesia, 39% of parents with children with acute lymphoblastic leukemia felt that they did not get support from the community.(11)

Stigma against cancer is still prevalent in Kenyan community as demonstrated by the fact that 15% of families did not disclose the diagnosis. Community education about childhood cancer would be useful in providing correct information to community members so as to enhance positive support to affected families. This can be achieved through mass media, schools or churches.

The parents interviewed received a lot of information and support from other parents in the ward. Eighty-seven percent of parents said they would not have understood their child's disease without the explanation they received from other parents. This could be mainly because fellow parents are able to express themselves in a language they can easily understand. Since they are also going through the same experiences parents can associate with one another more easily. This is an aspect that should encourage the formation of a parent support group in this setting.

In conclusion this study reveals that families in Kenya suffer a lot of economic turmoil when they have children undergoing treatment for cancer. It also reveals that CAM use is very widespread in these patients and that parents are not satisfied with the amount and manner of receiving information from doctors.

There were several limitations in this study. Parents could have given socially acceptable answers during interviews as the culture in Kenya does not encourage criticism. Parents were interviewed at different phases of their child's treatment and this means that they could have undergone different experiences. The perceptions of a parent whose child is just starting treatment is likely to be different from that of a parent whose child has finished treatment and is in remission. There could also have been a recall bias among those who had completed treatment.

Based on the findings of our cross-sectional study, we would like to make the following recommendations:

The national government through the ministry of health should provide more funds for the care of pediatric oncology patients. The government should focus on setting-up satellite pediatric oncology clinics so that the burden of travelling long distances by the patients is minimized. There should be focus on training more doctors in the field of pediatric oncology to reduce the patient to doctor ratio to allow more time for interaction between doctors, patients and their guardians.

The hospital should work on getting a facility near the hospital where patients and their guardians can stay in between cycles of chemotherapy. The hospital can partner with local and international charities to raise money for running the facility. The money raised through such collaborations can be used to help offset transport costs for very poor patients. The hospital should also ensure health workers undergo refresher courses on patient communication.

Doctors should work toward having a set out time for discussing with families about their child's illness especially at time of diagnosis and start of treatment. Doctors should also ensure they equip themselves with proper communication skills and use easy and appropriate language when talking to patients and families. They should also discuss CAM more openly with families as majority of them use it at some point during their child's illness. Doctors, in conjunction with other help workers like social workers and psychologists, should help parents in forming a support group that meets regularly.

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CHAPTER 7

HEALTH-CARE PROVIDERS' PERSPECTIVES TOWARDS CHILDHOOD CANCER TREATMENT IN KENYA††

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ABSTRACT

This study explores the perspectives of health-care providers on childhood cancer treatment in Kenya. A self-administered questionnaire was completed by 104 health-care providers in January and February 2013.Seventy six percent of the health-care providers believe that cancer is curable. More doctors than other health-care providers believe that cancer can be cured (p=0.037).Majority of health-care providers (92%) believe that most children with cancer will not be able to finish their treatment due to financial difficulties. They believe that prosperous highly-educated parents adhere better with treatment (88%) and that doctors adhere better with treatment for prosperous highly-educated parents (79%). According to 74% of health-care providers, quality of care is improved towards prosperous highly-educated parents (74%). Most health-care providers report to give more explanation (71%), work with greater accuracy (70%) and use less difficult vocabulary (55%) to prosperous more educated families. Only 34% of health-care providers reported they feel more empathy towards patients from prosperous families. Reasons for non-adherence with the protocol according to health-care providers are: family refuses drugs (85%), inadequate supply of drugs at pharmacy (79%), child looks ill (75%), and financial difficulties of parents (69%). Health-care providers' health beliefs and attitudes differ between families with high versus low socio-economic backgrounds.

Abbreviations: *MTRH - Moi Teaching and Referral Hospital; HCP - health-care providers*

INTRODUCTION

The low-income countries bear a greater burden of childhood cancer as compared to the high-income countries. Eighty per cent of all childhood cancers and 90% of the deaths occur in low-income countries (Magrath et al., 2013; Pritchard et al., 2013; Rodriguez-Galido et al., 2013; Sillivan et al. 2013).

Treatment abandonment is the leading cause of treatment failure in low-income countries. Several patient-related factors may contribute to treatment abandonment. These include low socio-economic status, low level of parental education, prolonged travel time to the hospital as well as the type of cancer.It is also recognized that health-care providersrelated factors may contribute to abandonment of therapy. Poor provision of information as well as poor communication skills of doctors enhances abandonment as the parents often do not understand the necessity of treatment continuation in their child. In addition, not all health-care providers may believe in the curability of cancer and effectiveness of chemotherapy. It is not possible for the health-care providers to enforce treatment adherence when they do not believe in the treatment offered (Arora et al.,2010; Mostert et al., 2011; Arora et al., 2007).

In Kenya more than 50% of the children with cancer abandon therapy and only 20% have event-free survival (Mostert et al., 2012).The perspectives of health-care providers towards childhood cancer treatment have not been extensively studied in Africa. This study aims to provide insight into the medical team's health beliefs and attitudes towards parental financial difficulties, protocol adherence, parental education and communication in an academic hospital in Kenya.

METHODS

Setting

The study was carried out at the Moi Teaching and Referral Hospital (MTRH), Eldoret in Western Kenya. Kenya is located in the Eastern part of Africa and has a population of about 42 million people. Half of the population lives on less than 2 dollars a day (Kenya National Bureau of Statistics, 2009).

MTRH is a tertiary referral hospital that serves a catchment area of about 18 million people. The hospital takes care of about 120 new pediatric oncology patients every year(Mostert etal., 2012)

The pediatric oncology unit is housed within the pediatric wards. The pediatric wards have 72 beds of which 12 are allocated to pediatric oncology. There are 15 pediatricians of whom one is dedicated to the oncology unit. The other pediatricians are usually involved in the diagnostic process for the oncology patients, taking care of the patients during night and weekend shifts, and whenever patients cannot be transferred to the oncology unit due to lack of space. The day to day care of the patients is usually in the hands of medical and clinical officers. The nurses and other support staff(social workers, physiotherapists, occupational therapists, nutritionists, and psychological counselors) are involved in the care of the children and they rotate from one section to another every 6 months. Child life workers in the playroom provide daily activities and information about treatment to parents and children.

MTRH has two models of service provision: the public and private systems. The private system is more expensive and it serves those who are in the middle or upper socio-economic classes and those who have private health insurance schemes. Patients in the private facilities get more spacious accommodation as well as faster and more efficient services compared to the ones in the public wards(Kenya National Bureau of Statistics, 2009). In general, patients in the private systems are more prosperous and regarded as better educated than patients attending the public systems.

Study Design

This was a cross-sectional study using a self-administered structured questionnaire. All 133health-care providers working in the pediatric department of MTRH were requested to fill in the questionnaire at home or in the hospital.

The questionnaire covered health-care providers' health beliefs and attitudes towards parental financial difficulties, protocol adherence, parental education and communication. To evaluate the questionnaire's statements, health-care providers were able to choose from two, three or four-point rating scales.

A panel of Kenyan, Indonesian, American and Dutch doctors developed the questionnaire which was pilot-tested for its content, clarity and for cultural sensitivities on 5 Kenyan health-care providers. Small adaptations were made on basis of the pilot-test. The questionnaire was anonymous. Participants self-identified their professional title as pediatrician, medical officer, clinical officer, nurse, social worker,

physiotherapist, occupational therapist, nutritionist, psychological counselor or day-care worker which was the sole demographic variable noted. Participants were assured that their answers would remain confidential. This study was approved by the Institutional Research Ethics Committee of MTRH.

Data Analysis

Frequency distributions were calculated. Reliability of items in this study was established. The Mann-Whitney test was used to compare differences in health beliefs between doctors and other health-care providers. Data management and analysis were accomplished with SPSS version 20.0.

RESULTS

During January and February 2013, questionnaires were handed out to all 133 health-care providers (hcp) of the pediatric department. Table 1 illustrates that 104 hcp (response rate 78%) returned their questionnaires. Cronbach's alpha coefficient varied between 0.71 and 0.89.

Table 1. Health-care providers participating in questionnaire study

Health-Care Providers	N	Response Rate (%)
Pediatricians	9	69
Medical officers	4	80
Clinical officers	13	81
Nurses	41	71
Social workers	4	100
Physiotherapists	4	100
Occupational therapists	3	100
Nutritionists	2	100
Psychological counselor	3	100
Child life workers	21	88
Total	104	78

Health Beliefs

Figure 1 illustrates causes of cancer in childhood according to hcp (n=104). Cancer is curable according to 76% of hcp, 13% are uncertain and 12% disagree. However, almost all children with cancer die according to 38% of hcp, 11% doubt this and 52% disagree. In order to cure cancer, the full length of treatment must be completed according to 99% of hcp. Ninety-two percent of hcp believe most children will not be able to complete treatment as a result of financial difficulties, 4% are uncertain and only 4% disagree. Table 2 shows health beliefs of doctors (pediatricians, medical officers, clinical officers, n=26) versus other hcp (n=78). Significantly more doctors than other hcp believe that cancer can be cured.The chance of cure increases for patients with prosperous and highly-educated parents according to 63% of hcp.

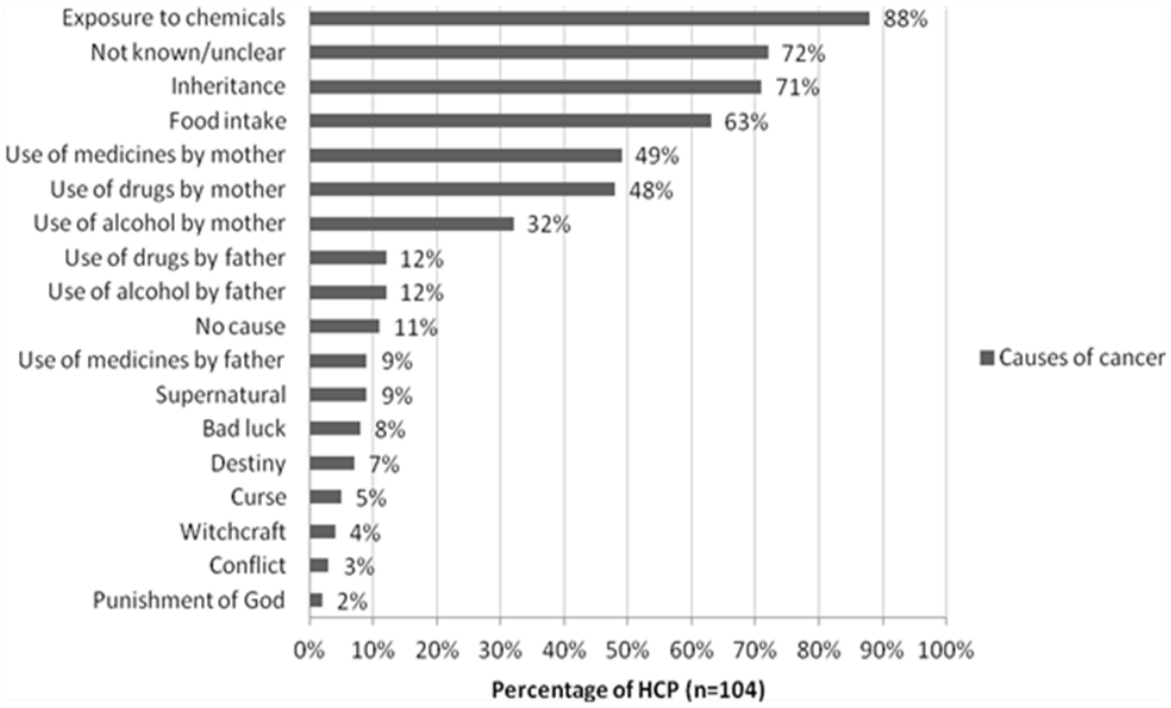

Figure 1. Causes of childhood cancer according to health-care providers (n=104)

Table 2. Health beliefs of medical doctors (n=26) versus other health-care providers (n=78)

Statements:		**Doctors**		**Other hcp**		
		Total	Count	Total	Count	*P*
Health of children with cancer is beyond doctor's control and determined by luck, fate or God	Agree	26	0 (0%)	77	16 (21%)	ns
	Uncertain		3 (12%)		4 (5%)	
	Disagree		23 (89%)		57 (74%)	
Health of children with cancer can be influenced by health-care providers	Agree	26	25 (96%)	76	71 (93%)	ns
	Uncertain		0 (0%)		2 (3%)	
	Disagree		1 (4%)		3 (4%)	
Cancer can be cured	Agree	26	24 (92%)	78	55 (71%)	0.037
	Uncertain		0 (0%)		13 (17%)	
	Disagree		2 (8%)		10 (13%)	
Almost all children with cancer die	Agree	26	7 (27%)	78	32 (41%)	ns
	Uncertain		1 (4%)		10 (13%)	
	Disagree		18 (69%)		36 (46%)	
Cancer is cured once the children appear healthy again	Agree	26	0 (0%)	78	3 (4%)	ns
	Uncertain		4 (15%)		14 (18%)	
	Disagree		22 (85%)		61 (78%)	
In order to cure cancer, the full length of treatment must be completed	Agree	25	25 (100%)	76	75 (99%)	ns
	Uncertain		0 (0%)		0 (0%)	
	Disagree		0 (0%)		1 (%)	
Surgery on cancer patients spreads the disease	Agree	25	0 (0%)	78	12 (16%)	ns
	Uncertain		5 (20%)		15 (19%)	
	Disagree		20 (80%)		51 (65%)	
If cancer patients receive surgery their chance of survival decreases	Agree	26	3 (12%)	77	11 (14%)	ns
	Uncertain		3 (12%)		12 (16%)	
	Disagree		20 (77%)		54 (70%)	

Financial Difficulties

The vast majority of hcp (97%) asks parents about their financial situation and possible financial difficulties. Forty-three percent of the hcp ask the families whether some aspects of treatment should be postponed or withheld due to financial difficulties. Table 3 highlights the attitudes of health-care providers (n=104) towards prosperous and highly-educated parents, as compared to poor less-educated parents.Sixty-nine percent of hcp believe that the quality of care improves when a patient has prosperous and highly-educated parents. Towards these patients, hcp stated that they give more elaborate explanations (71%),are more accurate (70%), pay more attention (59%) and tend to show more interest (56%). Some hcp report that they have more respect (51%), pay more frequent visits (50%), and spent more time per visit (45%) towards prosperous and highly-educated parents.However, approximately half of all hcp (54%) mention that there is no difference in empathy towards prosperous highly-educated versus poor less-educated parents.

Protocol Adherence

The decision to start or not start cancer treatment is reported to be influenced by: type of cancer (88%), nutritional status of patient (87%), motivation of parents (72%), motivation of doctors (55%), health-insurance coverage of patient (55%), and financial situation of parents (50%). Strict doctor adherence with prescribed dosage and timing of chemotherapy administration is crucial and improves the survival of children with cancer according to 97% of hcp. In total 79% of hcp state that doctors' adherence is improved towards children with prosperous highly-educated parents, as compared to poor less-educated parents. Figure 2 highlights the reasons for non-adherence with protocol according to health-care providers (n=104). The most frequently reported reasons for not following the prescribed schedule and dose are: family refuses drugs (85%), inadequate supply of drugs at pharmacy (79%), child looks ill (75%) and financial difficulties of parents (69%). Strict patient adherence with prescribed dosage and timing of medication is crucial and improves the survival of children with cancer according to 96% of hcp. Eighty-eight percent of hcp state that children with prosperous highly-educated parents adhere better with prescribed treatment compared to poor less-educated parents. Towards children with prosperous highly-educated parents, hcp reported to provide treatment more completely as prescribed by the protocol (63%), and give more intense chemotherapy (49%).

Table 3. Attitude of health-care providers (n=104) towards prosperous and highly-educated parents, as compared to poor less-educated parents.

Attitude towards prosperous highly-educated parents		**Total**	**Count**	**Attitude towards prosperous highly-educated parents:**		**Total**	**C*ount***
Vocabulary	More difficult	103	18 (17%)	**Expectation towardsadherenceof parents**	Improved	101	89 (88%)
	Less difficult		57 (55%)		Worsened		2 (2%)
	No difference		28 (27%)		No difference		10 (10%)
Explanation	More elaborate	103	73 (71%)	**Expectation towardsadherenceof doctors**	Improved	103	81 (79%)
	Less elaborate		20 (19%)		Worsened		3(3%)
	No difference		10 (10%)		No difference		19 (18%)
Respect	More respect	101	52 (51%)	**Time taken per doctor visit**	More time	104	47 (45%)
	Less respect		9 (9%)		Lesstime		28(27%)
	No difference		40 (40%)		No difference		29 (28%)
Empathy	More empathy	104	33 (32%)	**Frequency of visits**	More frequent	98	49(50%)
	Less empathy		15 (14%)		Less frequent		14(14%)
	No difference		56 (54%)		Nodifference		35 (36%)
Interest	More interest	103	59 (57%)	**Treatment according to protocol**	More complete	104	66 (63%)
	Lessinterest		6 (6%)		Less complete		4(4%)
	No difference		38 (37%)		No difference		34(33%)
Attention	More attention	104	61(59%)	**Chemotherapy**	More intense	101	49(49%)
	Lessattention		6 (6%)		Lessintense		5(5%)
	No difference		37(36%)		No difference		47 (47%)
Accuracy	More accurate	97	68 (70%)	**Side-effects**	More severe	102	10 (10%)
	Less accurate		3 (3%)		Less severe		35(33%)
	No difference		26(27%)		Nodifference		57 (56%)
Expectation towards chance of cure	Increased	104	66 (63%)	**Quality of care**	Improved	97	72 (74%)
	Decreased		7 (7%)		Worsened		0(0%)
	No difference		31 (30%)		Nodifference		25 (26%)

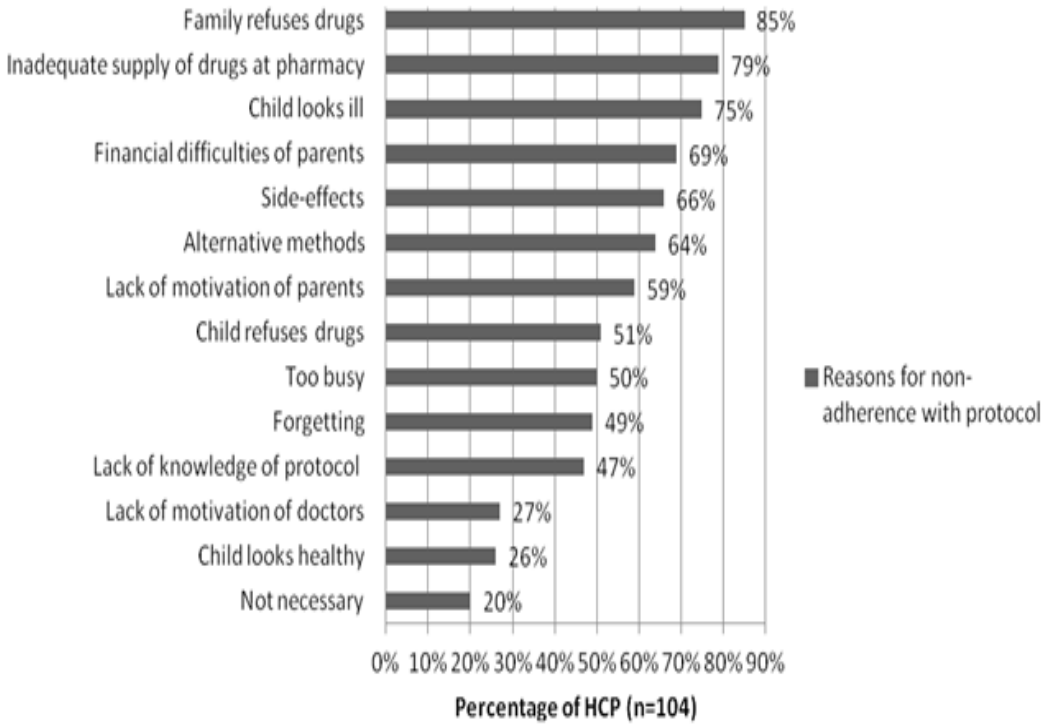

Figure 2.Reasons for non-adherence with protocol according to health-care providers (n=104)

Parental Education and Communication

It is crucial to give clear explanations to patients and parents to ensure cooperation and adherence to the chemotherapeutic regimen according to 99% of hcp. Medical vocabulary that patients and parents do not understand is used by 63% of hcp. Surprisingly health-care providers indicated that they use less difficult vocabulary (55%) towards families with prosperous highly-educated parents as compared to poor less-educated parents. Some difficulties in openly discussing the illness and its treatment with patients and parents are experienced by 71% of hcp, and severe difficulties are encountered according to 18%.Poor communication between patients, parents and doctors decreases the prognosis of children with cancer, according to 73% of hcp.Education about cancer and its treatment makes parents more afraid or depressed about the future and therefore parents prefer not to know, according to 19% of hcp, 11% are uncertain, 70% disagree. There is no time to give extensive explanations about the disease and treatment to parents and patients according to 18% of hcp, 5% are uncertain and 77% disagree. Because parents can have difficulties to understand the information the health-care providers give about disease and treatment, 42% of hcp say

that they always verify if parents understand the information given. Important information is always repeated by 35% of hcp.

DISCUSSION

This study explored the beliefs of hcp towards childhood cancer treatment in a low-income country. Significantly more doctors believed that cancer can be cured compared to the other hcp. This could be as a result of the doctors having more knowledge and experience regarding childhood cancer treatment.Nevertheless, with low survival rate observed in low-income countries, it is understandable that some Kenyan hcp have a negative perspective on the curability of cancer. The health beliefs regarding other aspects of childhood cancer were similar between the doctors versus other hcp. Similar findings were observed in Indonesia where there were also no major differences in health beliefs between doctors and other hcp. (Mostert etal., 2013)

Provision of clear information to parents is paramount in ensuring adherence to cancer treatment. (Mostert et al, 2013)This study highlights the fact that the majority of hcp use medical vocabulary when discussing with parents about the condition of their children. English is one of the official languages in Kenya, however, it is learned in school and only used as the means for communication by those who have completed up to high school level of education and are more affluent(Constitution of Kenya, 2010; What languages are spoken in Kenya, 2013).Doctors communicate among themselves in English. Most of the patients and their parents have difficulties communicating in English and are more fluent in Kiswahili and other local dialects. In our study the hcp attest to using less difficult vocabulary when dealing with prosperous highly-educated parents. This could be because the hcp are able to communicate more easily and get more relaxed when discussing with more educated parents as they can easily communicate with them in English. In order to communicate with the families on the public wards doctors need to speak Kiswahili and most of the medical terminologies are not easy to explain in Kiswahili. A similar situation was noted in Indonesia where 88% of the hcp reported using language that the parents could not understand(Mostert etal., 2013). In Kenya 42% of the hcp verify with the parents whether they have understood the information which is important in improving the parents understanding.

The hcp reported having difficulties discussing with parents about the condition of their children while admitting that poor communication between hcp and patients leads to poorer outcomes. In Indonesia a

similar situation was found where 81% of the hcp said that poor communication between parents and hcp would lead to poor outcomes and 57% stated they had difficulties discussing about cancer with the parents.(Mostert et al., 2013) Most of the hcp in Kenya may not have had adequate training on how to communicate bad news to parents or patients and this may further explain why they experience these difficulties.It could also arise from the fact that the hcp are scared of cancer or they do not understand it sufficiently enough to be able to pass on the right information to the parents.

The hcp believed that patients' and doctors' adherence with the protocol are important to achieve cure. Almost all hcp were convinced that most children will not be able to finish treatment due to financial difficulties. The vast majority of hcp believed that the childrenwithprosperous highly-educated parents adhere better with treatment. This could be because they get more clear explanations about the disease and required treatment than the poor less-educated parents. This could also be because these affluent families can simply afford to complete treatment. In addition, the more educated parents are also likely to be more aware of their rights and more vigilant as well with the treatment plans. The vast majority of hcp believed that doctors' adherence with treatment is improved towards children with prosperous highly-educated parents.Hcp are more likely to provide more complete treatment when dealing with these privileged families. These patients are likely to be taken care of in the private wing of the hospital where they get attention from only one specific doctor. The patients in the public wards do not get to be attended to by a specific doctor. Usually the doctor on duty on a particular day would be the one to take care of them. The doctors also earn extra money by taking care of patients in the private wing. This would have an effect on the time they spend with these patients and offer extra care. Since these patients are richer they also can afford more treatment modalities than the poorer patients.

Interestingly, we found that the most commonly reported reasons by the medical team for non-adherence with prescribed treatment schedules are beyond the control of hcp and concern patients, parents and the pharmacy. This would therefore mean that the hcp feel that they have little control over the adherence or non-adherence with protocol. In Indonesia the hcp also believed that the reasons for non-adherence had more to do with factors beyond their control (Mostert et al., 2013; Sitaresmi et al., 2008).This may indicate that the hcp have a high external health locus of control. Studies among patients previously

illustrated that health locus of control can be a predictor of better adherence with cancer treatment(Iskandarsyah et al., 2014) Patients with internal health locus of control think that their health condition is determined by their own actions. In contrast, patients with external health locus of control believe that their condition results from external situations. Patients with internal health locus of control are assumed to better adhere with treatment(Hiller et al., 2014; Konkoly et al., 2014; Reitzal et al., 2013) Although the health locus of control concept has previously not been extensively investigated for hcp, our study findings suggest that hcp themselves have a high external health locus of control. This may adversely affect their own attitudes and adherence with cancer treatment. It could also affect the information they give to the patients and their families. The hcp may inform the patients and their families that they have little control over the outcome of their illness and hence reduce the families adherence.

The parental financial status has an effect on many aspects of the patients' treatment. The majority of hcp agreed that the quality of provided care and chance of cure is improved towards more affluent patients and their families. This could be related to the financial benefits accrued especially by the doctors.It is interesting to note that the level of empathy does not change depending on the parents' economic status. This may mean that the more attention the prosperous patients get is based mainly on the financial gains for the hcp. The doctors employed by the government of Kenya engage in dual practice. This means they work in private hospitals although they are hired and paid on a full time basis in the public hospitals. They earn extra money for each patient they see in the private hospitals. This often leads to a situation whereby they spend more time in the private hospital to the detriment of the patients in the public hospitals (Ariadna, 2001;Chankora et al., 2009; Paulo et al., 2014)

This study had several limitations. Some of the respondents could have given socially acceptable answers.Not all hcp had worked at both the public wards and private wing. Also not all respondents had the same exposure to or training about childhood cancer.

We recommend that the hcp working with children with cancer get specific training on communication with the parents and patients. In Kenya this can be achieved through the Kenya Society of Hematology and Oncology which is the body that brings together all the health workers in the field on oncology in the country. Training on

communication should be incorporated in the curricula of medical training institutes in the country. More staff need to be added to work in this area as well and those currently working there should be encouraged to spend more time discussing the children's illness with the poorer families. The staff should also attend refresher courses on treatment and outcomes of pediatric oncology patients so that they are able to appropriately educate patients and their families.

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CHAPTER 8
CORRUPTION IN HEALTH-CARE SYSTEMS AND ITS EFFECT ON CANCER CARE IN AFRICA[‡‡]

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SUMMARY

At the government, hospital, and health-care provider level, corruption plays a major role in health-care systems in Africa. The returns on health investments of international financial institutions, health organisations, and donors might be very low when mismanagement and dysfunctional structures of health-care systems are not addressed. More funding might even aggravate corruption. We discuss corruption and its effects on cancer care within the African health-care system in a sociocultural context. The contribution of high-income countries in stimulating corruption is also described. Corrupt African governments cannot be expected to take the initiative to eradicate corruption. Therefore, international financial institutions, health organisations, and financial donors should use their power to demand policy reforms of health-care systems in Africa troubled by the issue of corruption. These modifications will ameliorate the access and quality of cancer care for patients across the continent, and ultimately improve the outcome of health care to all patients.

Abbreviation: *CPI - Corruption Perceptions Index*

INTRODUCTION

In many African countries, international financial institutions, health organisations, and donors finance an important portion of the health sector, and may determine health policies in these countries.[1,2] Despite their potential influence, these agencies have not sufficiently used their power to ameliorate the access and quality of medical care for people with low incomes or from poor socio-economic backgrounds.[1] Why should African countries not determine their own health policies independently of these agencies? The answer is clear and simple: because of widespread corruption.[3-8] In this paper, we discuss the scale, susceptibility, and effect of corruption on health-care systems in Africa, as well as discussing the role both African and high-income governments can play in delivering quality health care to patients with cancer across the continent.

Scale of Corruption

The Corruption Perceptions Index annually scores countries worldwide on how corrupt their public sectors are perceived to be. Countries are scored on a scale from 0 (highly corrupt) to 100 (very clean). The index is currently lower than 50 in 91% of African countries, although some geographical variation exist. In 2013, all countries in northern and central Africa had scores lower than 50, as did 88% of countries in western and eastern Africa and 83% of countries in southern Africa.[4,9] Additionally, the score is below 50 in 89% of other low-income and middle-income countries worldwide. By contrast, 21% of high-income countries have a score of less than 50; high-income countries such as the USA, Canada, Australia, and New-Zealand, and all countries in northern and western Europe, have scores higher than 50.[4,9]

Corruption can be defined as an “abuse of entrusted power for private gain.”[6] Three forms of corruption can be distinguished: bribery (a clandestine order for additional money for civil services); extortion (demands for gifts and favours for civil services or depleting funds for private intents); and nepotism (allocation of public service contracts to relatives or acquaintances, irrespective of their competence).[10,11] Corruption purposely subordinates public welfare to private welfare. Corruptors’ behaviour is denoted by dualism: their conduct emerges from their occupation and self-interest.[10,11] Corruption involves breach of trust, deception, repression, exploitation, disparity and indifference to victims’ torment. Individuals on low incomes and from poor socioeconomic backgrounds are disproportionately affected by corruption compared with those on high incomes and with higher socioeconomic backgrounds because they cannot afford bribes and private alternatives.[11-13]

Table. African country-specific examples of corruption

Corruption	African country-specific examples
Lower CPI is associated with poorer population health	Burkina Faso [20], Chad [20], Comoros [20], Congo [20], Ethiopia [20], Ghana [20], Ivory Coast [20], Kenya [20], Malawi [20], Mali [20], Mauritania [20], Mauritius [20], Morocco [20], Namibia [20], Senegal [20] South-Africa [20], Swaziland [20], Tunisia [20], Zambia [20], Zimbabwe [20]
Western businesses bribe African leaders and pollute the African environment	Angola [16], Congo [16], Democratic Republic of Congo [16], Equatorial Guinea [16], Gabon [16], Ghana [16], Guinea [16,73], Liberia [16], Nigeria [16], Senegal [16], Sierra Leone [16], Somalia [16], South-Africa [16], Zimbabwe [74]
Western bank accounts hide misappropriated funds, tax evasion and money laundering	Algeria [15], Angola [16], Cameroon [16], Cape Verde [15], Congo [16], Democratic Republic of Congo [15], Djibouti [15], Egypt [15], Equatorial Guinea [16], Gabon [16], Ghana [16], Guinea [16], Ivory Coast [15], Kenya [15,16], Nigeria [15,16], Rwanda [15], Senegal [15], Sierra Leone [15], South-Africa [15], Togo [16], Tunisia [15], Zaire [16], Zimbabwe [15,74]
Misappropriation of funds and aid	Burkina Faso, Burundi [1], Cameroon [21], Chad [21], Ethiopia [8], Ghana [13,21,24], Kenya [8,21,28], Liberia [3], Malawi [5], Morocco [6], Mozambique [21], Namibia [21], Nigeria [13,21], Rwanda [13,21], Senegal [13,21], Sierra Leone [8], South-Africa [6], Sudan [8], Tanzania [13,21], Uganda [13,19,23], Zambia [5]
Procurement, theft and resale of drugs and medical equipment	Cameroon [5], Cape Verde [6], Central African Republic [5], Chad [5,21], Congo [5], Democratic Republic of Congo [5], Ethiopia [5,13,38], Ghana [5,21], Kenya [5,6,21,28], Madagascar [5], Malawi [5], Mali [5], Mozambique [6], Nigeria [5,13], Rwanda [5], Senegal [5], Tanzania [5,21], Uganda [5,6,13,19,21,23,35], Zambia [5,21], Zimbabwe [5]
Lacking quality control of drugs and medical equipment	Cameroon [5], Central African Republic [5], Chad [5], Congo [5], Democratic Republic of Congo [5,8], Ethiopia [5,8], Ghana [5], Ivory Coast [8], Kenya [5,6], Mali [5], Nigeria [5,7], Rwanda [5], Senegal [5], Tanzania [5], Uganda [5], Zambia [5]
Low government salaries, physician dual practices and absenteeism	Burundi [1], Chad [21,33], Ghana [21], Egypt [37], Ethiopia [13,38], Kenya [21,28], Mozambique [13], Nigeria [13,22], Tanzania [5,21], Uganda [13,19,21,23,33,35], Zambia [21]
Informal payments	Burkina Faso [5], Burundi [59], Chad [21], Democratic Republic of Congo [59], Ethiopia [13,38,59], Ghana [13,21], Kenya [6,21,28], Malawi [8], Morocco [6], Mozambique [13], Rwanda [59], South-Africa [6], Sudan [59], Tanzania [5,21,59], Uganda [8,13,19,35,21,23,59], Zambia [21], Zimbabwe [6]
Waiver procedures	Burundi [1,29,59], Democratic Republic of Congo [59], Ethiopia [59], Kenya [25,27,28], Rwanda [59], Sudan [59], Tanzania [59], Uganda [59]
Hospital detention practices	Benin [25], Burundi [1,29], Cameroon [25,27], Democratic Republic of Congo [1], Ghana [1,25,27], Kenya [1,25-29], Nigeria [25,27], Zimbabwe [1]

Effect on Economic Growth and Development

Corruption reduces economic growth and development because of its effects on investment, taxation, public expenditures and human development.[14] Corruption subverts the efficiency of government institutions and hinders equal distribution of resources and income across populations. For instance, corruption can decrease the ratio of investment to gross domestic product and can lead to tax evasion. In countries where corruption is an issue, government officials allocate more public funds on opportunities for private gain than on public welfare.[14] Annually, billions of US dollars from international and national funds and potential taxable income are stolen from the African continent (table).[15,16] Although political leaders from African countries vowed to spend at least 15% of their annual budget to improve the health sector by 2015, almost no African countries have accomplished this Millennium Development Goal.[17] This deficit is particularly damaging because Africa is confronted with a high burden of disease. Proper investment in the health sector could substantially a loss of income from the African population and stimulate economic growth and development.[14,18]

Susceptibility of Health-Care Systems

The scale of corruption within a health-care system often mirrors the society that the system functions in. Although most health-care providers and stakeholders are honest and involved in the health sector for fundamentally altruistic reasons, the problem of corruption in African health-care systems needs to be realistically addressed. Improvements can be made that can benefit not only patients, but also all benevolent health-care providers and stakeholders. We provide a general overview of the scale and issues of corruption in African health-care sectors and do not judge the extent of corruption or the measures of prevention in different settings across Africa.

Some characteristics of health-care systems make them more susceptible to corruption: a large number of implicates players (international financial institutions, health-organisations, donors, government officials, hospital administrators, health-care providers, suppliers, health insurers, patients, and the general population)and the complexity of their interactions; imbalance of medical knowledge between various players (eg. between doctors and patients, between pharmaceuticals and procurement officers); uncertainty in the health-market makes prediction difficult when patients need specific types of health-care services and how to best allocate limited resources; difficulties in distinguishing between honest mistakes and corrupt

practices; and poor record-keeping.[6,11] All these aspects can be applied to oncology care in Africa. The effect of corruption in cancer care cannot be addressed without first addressing the structures of health-care systems themselves and the interaction with various individuals at the government, hospital and health-care provider level (figure).

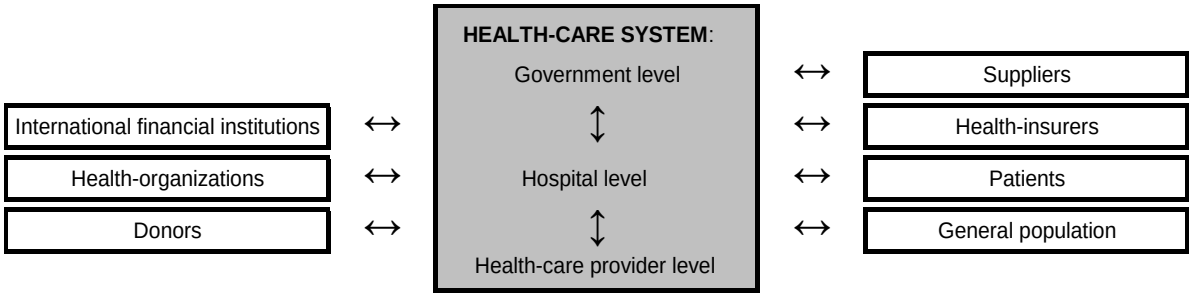

Figure. Interaction of multiple players within the health-care system at the government, hospital and health-care provider level

EFFECT ON THE STRUCTURE OF HEALTH-CARE SYSTEMS

Corruption has a major effect on the structure of health-care systems in Africa. These systems are solely as strong as their management at the government, hospital and health-care provider level.[13,19]Health-care delivery relies on effective assembly and allocation of financial resources, personnel, and supplies in a prompt, transparent manner across a country. This system demands a structure in which budgets, health-care providers, and supplies are consistently monitored, correct performances are rewarded, and misconduct is penalized. If monitoring systems and incentives for good staff performance and discipline and accountability for misconduct are not provided, management of health-care systems is disempowered and corruption can affect the health-care structure as a whole (panel 1).[13] As a result, performance of health-care services can be dismal and the general population can be disadvantaged.[6,20]

Panel 1. Key components of health-care system structures affected by corruption

- Absent or failing monitoring-systems for health budgets, personnel, and supplies
- No reward for good performance
- No punishment for misconduct
- Salaries for health-care providers in public hospitals not in line with their educational background, skills, and training
- Physician dual practices, absenteeism, and informal payments

Government Level

Good governance is decisive in enabling structures of health-care systems to run well but is unfortunately not present in many African countries.[6,13,19] Corruption and distortion of health policies start with health ministers and government officials who pillage public health budgets or international and national funds for private gain.[9,21] Depletion of publicfunds can happen during conveyance from public treasuries to ministries, from ministries to hospitals, and within hospitals.[13]Inadequate prioritisation of projects is also an issue. Health ministers and high-ranking officials create health-care facilities in areas where these services are not useful or practical but as an attempt to gain support from those areas during elections. Most of these projects consume funds that would have otherwise been put to better use.[6] As a result of looted health budgets, governments can reduce expenses through underpayment of health-care providers. Doctors working in public hospitals are poorly remunerated and excellence is not rewarded, which can lead to poor motivation. Thus, quality of medical care deteriorates for those patients on low incomes who are confined to public hospitals.[6,19]

Governments should supply public hospitals with needed drugs and medical-devices. Scarcity of inventory systems, straightforward policies, and pricelists for medical goods enables the rise in corruption within the health-care sector.[6,19]Often, governments are the only regulators and have absolute procurement power over these assets.Thus, opportunities for officials and suppliers to increase their wealth are rife through kickbacks, overbilling or grafts.[6] Government-officials determine what medicines and in what amounts need to be acquired from pharmaceutical companies. To receive promised kickbacks, excessive quantities of expensive drugs may be procured.[22]Selection of national essential drug lists might also be more determined by bribes of manufacturers than by recommendations of the WHO essential medicines list.Consequently, drugs on national lists might neither be the most cost effective nor the most suitable.[6] Moreover, access to supplies is not controlled, making them susceptible to theft, where those responsible are not held accountable for their actions. Officials can sell purchased medicines and medical devices, intended for use in public hospitals, to private hospitals, or on the black markets.[6,13]Some African governments might not regulate the quality and the price of products from pharmaceutical and medical device companies, which results in overpriced substandard medicines and medical devices.[6,19] Government officials can be bribed to ignore production, importation, and exportation of counterfeit drugs.[6]

Sale of public positions or promotions also plays a key part in the subversion of health-care systems in Africa.Unqualified personnel who are ready to pay bribes can get better jobs than can those who are unwilling to pay bribes. This creates a profound discrepancy between the competences and job requirements of these individuals. Recently hired or promoted employees engage in more corrupt practices to fulfill illegal monetary requirements to sustain employment and career progression.[13,19,23]

Hospital Level

Health-ministries can transfer reduced health budgets to public hospitals. Subsequently, these hospitals might not receive sufficient revenues from government funding, financial donors, and patient reimbursements to operate effectively.[6,13,19,22] Moreover, funds are often misappropriated. Administrators of public hospitals might first take their illegal share from depleted health funding.[21,22,24] As a result of these plundered budgets, administrators are forced to cut public hospitals' expenses by ensuring that patients who cannot afford medical care do not use it. Access can be hindered by demands for unofficial administration fees, or staff checking families' financial situations before diagnostics or treatment and sending home those patients who cannot afford treatment.[1,6,20] Some hospitals can both patients, or retain bodies of deceased patients until their families pay their medical bills.[1,25-29]

In some instances, public hospitals have instituted waivers to assist the poorest families' access to medical care.[13,25,27,28]Although in theory these procedures sound beneficial, inreality, waivers can be exploited and create extra opportunities for corruption.[25,27,30]Frequently, no clear rules or selection criteria exist. Waivers might not be made available to those who need them most or some individuals might be coerced to offer bribes for the waivers. Waivers can also be given to the rich and the powerful who might render favours in return.[13,28] Therefore, under these circumstances, waivers lead to more social injustice, corruption, and unequal access to medical care.[25,27,30]

As a result of inappropriate procurement, theft, and resale of drugs and medical equipment by health ministries, supplies can be out of stock, overpriced, and unaffordable to patients.[6,13,19,28] Accordingly, public hospitals are compelled to rely on donated supplies. Inadequate logistical management, little oversight and poor quality monitoring can lead to drugs and medical devices that have often expired or are counterfeit.[6,13]

Another major challenge in the African health-care sector is equipment maintenance.Engineers responsible for this task usually do not act fast enough whenever equipment needs to be repaired. Engineers often overprice the cost for repair and keep the profits for themselves. Corruption also exists when some engineers and technicians work with doctors to delay repairs or disable equipment so that they can send patients to private facilities or are paid commission by owners of these facilities. [31,32]

In public hospitals, already deficient medical supplies can be sold by administrators, health-care providers, and pharmacists to private hospitals or on the black market.[11] Substantial proportions of drugs and devices go missing. Depleted stocks canforce public hospitals and patients to buy from private pharmacies or distributors.[1] Illegal deals ensure that the referral of patients to these pharmacies and distributors leads to promised kickbacks.[19] Additionally, bribes can be used to obtain employment and promotions in public hospitalsl.[13,23]Personnel who refuse bribes can be exposed to retribution.[11,13]

Health-Care Provider Level

In many African countries, health-care providers in public hospitals are paid low salaries. Therefore, involvements in other economic activities during office hours or making use of possibilities for private gain through public health-care systems are ubiquitous.[6,19]

Health-care providers working at public hospitals are paid fixed monthly salaries irrespective of their performance and output. Doctors generally deem this payment too little to support their own families and subsequently attend various other jobs at private practices.[19,22,33] This combination of public and private employment is called physician dual practice. Doctors can improperly refer patients from public hospitals to their private practices in which every action implies direct remuneration. Subsequently, these new private patients receive preferential treatment at public hospitals in cases in which a facility or procedure is only available in the public hospital, forcing other patients at public hospitals to wait. [6,11]

Staffing at public hospitals is the utmost crucial component of health-care provision as hospitals cannot function without staff.[13,19,22,33] However, physicians having dual private-public practices lead to staff shortages in public hospitals. The term ghost workers refers to personnel who never attend public hospitals yet receive wages for their position in the public

profession.[13,34]Health-care providers often justify their absences in public hospitals by responsibilities at private practices,[13] and remorse by physicians for not attending to responsibilities at public hospitals is often scarce. General disregard exists in relation to the necessity of health-care workers to adequately staff public hospitals and to take care of the patients. Absenteeism of health-care workers is ubiquitous because public hospitals do not have systems to monitor and sanction staff who fail in their public responsibilities.[33,35]The culture within public hospitals is highly tolerant towards absenteeism.Absence of management and a manager's reluctance to confront doctors encourage other employees to also be absent during working hours.[13,33] As a result, high absenteeism and low productivity is widely reported in public hospitals.[13] Physicians are the most absent; however, all levels and types of personnel are less absent when physicians in charge are more present,[36] as when staff physicians and nurses are absent, interns, residents and auxiliary nurses are not supervised.[10]Understaffed health-care services therefore rely on untrained personnel without supervision.[37,38] No supervision also implies an underinvestment in the quality of future health-care providers.[13]In the public health-care sector, full-time salaries are thus paid to medical staff who only work part-time.[19] This mismanagement of pay results in closed departments and facilities, slow diagnostics, delays in treatment, arrears, underuse of medical equipment, waiting lists, prolonged time spent in hospital, ill-trained personnel, and eventually, adverse patient outcomes.[13,28,37,38] Thus, absenteeism and dual practices of physicians fundamentally undermine equal access and quality of health-care services to patients across the continent.[13,19,22,33]

Informal payments to doctors, nurses, and other personnel for health-care services that either should be given for free or that are higher than formal charges are widespread.[6,13,35,38]Medical staff can insist on bribes for every service they provide, such as registration, changing bed linen, giving injections, prioritization in queues for treatment, giving better care, and acquiring subsidised medicines.[13,22] Moreover, patients are not offered a choice: either bribes are paid or medical care is refused. Multiple payments are so rife in the health-care sector that patients can get confused about which payments are legal and which ones are not.[13] Informal payments can surpass families' annual income and result in serious financial debts.[13]

Location of private practices and private hospitals adjacent to public hospitals can contribute to the theft of drugs and medical devices.Stolen goods are either used by doctors in private practices, sold to private

hospitals, or sold on the black market.[19,35,36] Doctors can make deals with pharmaceutical and medical companies to only prescribe their expensive drugs or devices.[6] If families cannot afford these products, cheaper alternatives are not offered, and patients are sent home without care. Chronic drug shortages, malfunctioning equipment, inflated prices for medical devices, and drugs dispensed to non-existent patients affirm corruption is widespread within the African health-care sector.[13]

Health-care providers can use donated aid to benefit financially.[6,19,21] Monetary amounts can be immediately pocketed or charged to patients for donated drugs, whilst goods can be used or sold to private practices, or sold on the black market.[19]

INTERACTION OF MULTIPLE PLAYERS

Various players interact with health-care systems and might facilitate corruption at the government, hospital, or health-care provider level (figure). Policies of international financial institutes might sometimes aggravate corruption. For example, most African countries do not prioritise the health sector and spend only a small proportion of their annual budget on health. To build a sustainable health-care system, the World Bank introduced cost sharing in communities to raise health-sector revenues. This implied that patients had to pay for their medical costs to make the system and use of resources more financially efficient and enhance equitable access. However, strict user fees and hospital detention practices resulted, which further restricted access to health-care.[1,28,29]

Some donor agencies bribe government and hospital officials to allow their programs to run. Collusion of some donor representatives with officials occurs to provide mediocre services for private gain. Donor agencies sometimes use per diem policies that create opportunities for corruption. Per diems can lead, for instance, to retarding work, needless trainings, overstating time required for tasks, negative working environment in which people insist on payments for all activities, unfair acquisition by superiors of per diems meant for others, subsequent distrust of subordinates toward their superiors, and conflicts. Donors often do not understand local scenarios and insufficiently engage beneficiaries to make them understand what their project needs to achieve.[6,12,39]

Suppliers are known to overprice products or sometimes supply fake products either by collusion with procurement officials, or by taking

advantage of officials who know little about these health products. In oncology, where drugs and equipment are not common and new products come onto the market frequently, this collusion is widespread.[6,13,19,28.]

Public, commercial and non-profit health-insurance agencies can be swindled by other players in the health sector, such as doctors billing for unnecessary or undelivered procedures and patients using forged insurance cards, but can also be involved in corrupt practices themselves.Public health insurers can misappropriate funds or allocate funds for political gain.Commercial and non-profit health insurers can engage in fraudulent billing, illegally rejecting insurance claims, and bribing insurance regulators to ignore unlawful practices.[6]

Scarcity of information available for patients contributes immensely to corruption. Patients do not know what to expect from health-care systems and therefore cannot defend their rights and demand proper health care.[6,8] Conversely, some patients might underreport their capability to pay hospital fees or use insurance plans that do not belong to them. The general population also adds to the issue of corruption in health institutions by expecting to receive favours especially if friends or relatives run those institutions. Health-care workers are not looked upon favourably by their community if they do not extend favours to their friends or family.[10]

Cancer Care

Damage imposed by corruption on the structure of health-care systems has an irrefutable effect on the provision of cancer care in Africa (panel 2). To the general public, health ministries, public hospitals, and health-care providers are generally known to be corrupt and the law does not protect individuals seeking health care. Corruption generates social injustice and a feeling of insecurity in the general population.[10,13,28] Corrupt services in public health care might scare poor families and encourage them to use alternative treatment, such as herbal medicine or witchcraft.[1,25,40-43]

Reported cancer incidences are substantially lower than actual incidences in service areas of public hospitals, which might be mitigated by an avoidance of corrupt public health-care services.[1,20,44,45] Corruption might also invoke delays in people seeking health care, resulting in patients only being diagnosed at a late stage of the disease. By the time patients finally visit hospital, the disease is ofen no longer curable.[1,46,47]

As patients on low incomes are less able to pay bribes or afford private health-care alternatives, their access to cancer care is restricted: many low-income families are immediately sent home after diagnosis without receiving any cancer care. Other families will start treatment but high costs, additional bribes, and little access to available donations force them to stop treatment prematurely.[1,6,11]

In Africa, very few staff are appropriately qualified in the field of oncology, and their absenteeism greatly worsens the quality of care provided to patients. Oncology care is a specialty with complex protocols and patients who need multidisciplinary approaches for treatment. An absence of senior doctors to provide leadership results in delays in decision making or in wrong treatments being offered to patients. Because of the absenteeism of senior doctors, junior staff do not acquire appropriate knowledge and skills from mentorship. These junior doctors continue to practice medicine in a substandard manner and possibly pass on wrong information to other health workers.[37,38] Complex cancer cases are thus taken care of by rotating junior staff rather than supervised by experienced doctors. Residents, interns, and auxiliary nurses have little experience and knowledge of oncology protocols without the appropriate supervision.[30,36]

Chemotherapeutic protocols from high-income countries cannot simply be used in low-income countries.[30,48] Intensive chemotherapy needs supportive care facilities and trained personnel that are not present in low-income countries. In these countries, patients are often malnourished or have concomitant infections and therefore react differently to chemotherapy. Intensive drug schedules that are hazardous if not properly applied should be avoided.[48,49] Because senior doctors are working at private practices, unsupervised, inexperienced staff will more easily not adhere to complex protocols.[13] Not only should intensity of treatment be changed but also duration of treatment as medicines are often neither available nor affordable.[50] Therefore, less intensive, less toxic, shorter, and cheaper protocols than those used in high-income countries are needed.[30,48-50]

Doctors engaging in physician dual practices have no time to plan and execute research. As a result, the size of the cancer burden in Africa is not accurately documented and no local, applicable solutions to the problems are being explored. Subsequently, the level of cancer care is unlikely to improve for future generations.[51]

Because of the absence of medical staff, unavailable or malfunctioning imaging techniques, closed surgery rooms, non-functional laboratory facilities, inadequate drugs supplies, and closed hospital wards, waiting lists in public hospitals can be extensive.[6,11,13,31] These lists result in delayed diagnostics, late start or intermittent cancer treatment. Long waiting times enable cancer progression and reduce chances of survival.

Additionally, because of theft and resale, supplies of drugs and medical devices in public hospitals are frequently out of stock. Families are forced to buy medicines and materials from private distributors, which inevitably incur additional costs to the individual. If private alternatives are not available or affordable, adequate cancer treatment according to prescribed treatment schedules is made impossible for large swathes of the population.[11] Although a reduction in the price of generic anticancer drugs could decrease total costs of cancer care and improve access to medicine for those patients on low incomes, motivation to produce, distribute, and prescribe these drugs might be low because generic drugs provide less personal revenues and kickbacks for pharmaceutical companies, distributors, pharmacists, and doctors.[6,52] When regulatory authorities ignore the distribution of counterfeit drugs, they compromise the well-being of patients who receive inefficacious drugs.[6,19]

Panel 2. Effects of corruption on cancer care

Health-Care Providers	• Unmotivated medical staff due to low government salaries • No experienced medical staff available in public hospitals due to physician dual practices and absenteeism • Inexperienced medical staff provide cancer care without supervision • Difficulties in the application of complex chemotherapeutic protocols • Demand of informal payments by medical staff • Doctors improperly refer patients from public hospitals to their private practices • Disregard by medical staff of responsibility to take care of patients on low incomes • Poor cancer education for patients and families • No supervision of inexperienced medical staff implies underinvestment in quality of future health-care providers
Drugs and Medical Equipment	• Scarcity of drugs and medical devices at public hospitals • Drugs and medical devices are overpriced, substandard or counterfeit • Lack of motivation to use generic anticancer drugs by medical staff • Patients are forced to buy drugs and medical devices at private pharmacists or distributors, incurring additional costs • Selection of national essential drug lists done on the basis of bribes • Underuse and malfunctioning of medical equipment • Medical equipment in public hospitals is purposely disabled and repair is overpriced and delayed to improperly send patients to private health facilities • No access to donated drugs or medical devices for patients on low incomes
Treatment	• No or little access to cancer care for patients on low incomes • Closed departments and facilities • Long waiting lists • Delayed diagnostics and late or intermittent cancer treatment • Prolonged stays in hospital • Traumatising experience of hospital detention • Unfair waiver procedures without clear rules or selection criteria • Undertreatment, overtreatment, and mistreatment
Patients	• Bad reputation of public health-sector • Encouragement of alternative treatment • Lower reported incidence than actual cancer incidence • Delayed seeking of medical help and advanced stages of disease at diagnosis • Families drawn deeper into long-term poverty • Low adherence to cancer treatment • Abandonment of cancer treatment • Poor cancer survival

African populations often have low literacy levels and little notion of the need to proceed with chemotherapy once patients respond to initial treatment. As with any country, provision of clear information about cancer treatment is crucial to ensure long-term commitment.Yet, cancer education is not given by appropriately qualified doctors as they are too busy in private practice. Subsequently, poor families receive either no information or confusing messages by different residents, interns, and auxiliary nurses.[27,53,54] Therefore, insight into why it is important to complete prescribed protocols is absent in patients and medical teams.

Corruption from medical staff at times when patients are most vulnerable and desperately need medical attention creates profound distrust of health-care providers within the continent. Additionally, patients have no control over the amount and timing of bribes, which makes them feel powerless. In Africa, strong social hierarchical structures exist, which create a large gap between doctors and families on low incomes. This status and power gap makes poor families unable to defend their rights and thus they are forced to silently accept corrupt health-car abuses, despite being detrimental to their health. For health-care providers, families on low incomes are therefore easy targets for personal financial enrichment. Lack of respect for medical professionals reduces adherence to cancer treatment, as does patients' feeling of lack of control over their disease progression and treatment.[8,11,28,55] Thus, corruption in the health-care system stimulates abandonment of treatment, the most frequent reason for cancer treatment failure in Africa, which can lead to progressive or relapsed disease and, ultimately, death.[11,27,56-58]

Some patients who have unpaid medical bills are detained by the hospital. Detention of patients because of unpaid medical bills is highly distressing to families, who desperately try to find money to redeem their loved ones. Every extra day in detention increases the cost of medical bills, therefore families trying to buy patients out of hospital detention find it increasingly difficult to meet increasing payment demands. Some patients are completely abandoned inside hospital because of a lack of money to pay for bills.[25,27] Cancer treatment involves high costs and bribes during prolonged periods. Families often need to sell vital assets, such as land, harvest, or livestock, to pay for medical bills and bribes. However, these assets are needed for their livelihood and without them families are drawn deeper into poverty and cannot afford future medical care and bribes.[1,13,59] A vicious downward spiral evolves, resulting with

unfinished cancer treatments, unnecessary cancer deaths, and poor socioeconomic outcomes.[1,47,59]

Many collaborative programs between oncology departments in high-income and low-income countries are established to share knowledge and improve cancer survival in low-income countries.[60,61] Both partners share their interest in oncology expertise, but do not share the same sociocultural backgrounds. Frequently, high-income partners are driven to help patients in low-income countries but might not be aware of the pervasive corruption issue and how it affects cancer care in low-income countries.However, low-income partners work in corrupt health-care systems in which taking care of the poor is not prioritised. If preventive measures are not taken, donations might be corrupted.[30]

Few African countries have enacted legislation to ensure cancer prevention and treatment. However, in these countries that have, corruption can lead to allocated funds being diverted for personal gains, meaning that execution of cancer legislation does not work.[62]

Corruption can lead to undertreatment, when patients receive no or little cancer care, or overtreatment, when doctors inappropriately order more tests, procedures, and drugs than necessary so as to enhance personal profit; or to mistreatment with malfunctioning medical devices or counterfeit drugs.[6,22] All these strategies can eventually cause premature death.[63-66]

Moral Autonomy and Responsibility

The cultures of western countries have an individualistic orientation, whereas cultures in Africa are based on collectivism. In many collectivist societies, preservation of social harmony and culture of respect to those who hold higher positions are given priority. This set-up restricts the validity of other moral principles, such as helping those patients on low incomes. An individual therefore has restricted moral autonomy and responsibility. Of note, this collectivist society is not about creating social harmony or ideal situations, but about accepting, preserving, and not disturbing existing situations or social hierarchies. Subordinates should not criticise their superiors or demand them to uphold responsibilities. In fact, the reverse applies, as conduct of superiors becomes the role model. In Africa, behaviour is correct when it advances social harmony and hierarchy, but is wrong when behaviour disrupts this state.[67-71] Corruption thus starts at the top of the social hierarchy.[10] Corrupt misconduct of health ministers and government officials is imitated by the

administrators of public hospitals. Likewise, doctors are corrupt, which allows nurses and other health-care personnel to misuse their power for private gain, allowing a culture of corruption to become widespread and accepted.

Role of High-Income Countries

What is the role of high-income countries in facilitating the issue of corruption across the continent? What do high-income have to gain from an impoverished, illiterate Africa with corrupt regimes? Unfortunately, high-income countries have often sought to gain from Africa's rich natural resources, corrupt local leaders, and poorer subordinates.[16,72-74]

Governmental institutions, laws and values were installed during the colonial period to favour the small group of elite individuals from western countries and suppress the African majority. Education and better positions in public and commercial sectors were reserved for individuals from western countries. Monitoring systems to hold these individuals accountable for their corruption were absent. After independence was gained from colonial rule, those who struggled for independence were inexperienced in setting up and managing efficient governmental institutions. The previous corrupt centralised structures remain: now the African elite are favoured and the poor majority is disregarded.[10,72]

The colonial rules exploited Africa's natural resources for economic gain, favoured some local leaders, and repressed native inhabitants. At present, the political and business elite from high-income countries of technology, oil, mining, defence, engineering, property development and estate corporations still bribe leaders to safeguard contracts and influence government decisions. These business deals first profit the high-income countries, favour African leaders and civil servants financially, pollute the environment, and impoverish Africa's population. Without corruption, some businesses could lose their position in the world-market and adversely affect the economies of high-income countries and their citizens.[10,16,72,73]

The misappropriated money that denies Africans proper health and cancer care sits in the banks of high-income countries with comfortable Corruption Perception Index scores. High-income countries do not choose to stop their banks from accepting plundered funds from African politicians and civil servants, they do not do due diligence and do not question the origin of their corrupt fortune.[15,16,73,74]

Although high-income countries like to perceive themselves as the watchdog of world order, their political leaders are remarkably silent about the part their businesses play in stimulating corruption in Africa. Also, little effort has been made to either stop bankssituated in these high-income countries from being safe havens for looted African budgets or to return stolen monies. Why? Most likely because this situation is not in their economic interest.[16,72-74]

Additionally, the media in these high-income countries, including television, radio, newspapers, and medical scientific journals, seem reluctant to publish the true magnitude of corruption in Africa and the extent of implication these high-income countries have in facilitating the issue of corruption, perhaps in fear of reprisal of multinationals, losing advertising revenue or readership, and discouraging outreach projects.[16,75] Without realistic reports, crucial awareness cannot be raised and improvements for Africa's population are made impossible.

RECOMMENDATIONS

Corruption is a deeply-rooted, multifaceted and complex problem affecting whole societies in Africa, not just the health-care sector.[22,71] Unfortunately, no easy solutions exist to stop the issue of corruption and its effects from spreading.[6,13,19]

Frequently, efforts to improve access and quality of medical care for patients focus on funding direct needs such as medical supplies. The structure in which health-care systems function is usually ignored,[13,33,35,38] yet, the structure perpetuates corruption and hinders access to, and quality of, medical care for poor people. Well intended funding might have little or no effect, and could even aggravate corruption.[13,33,38,75] For example, extra funding for chemotherapy or medical equipment has negligible effect on outcomes for patients with cancer when no experienced doctors in public hospitals are motivated to help treat patients on low incomes. Hence, the focus should be on health-care systems affected by corruption at the government, hospital and health-care provider levels.

Panel 3. Recommendations to address corruption in African health-care systems

International Financial Institutions, Health-Organisations, and Donors:

- Pressurise governments to use development assistance to address key components of health-care systems: monitoring-systems, rewards, punishments, decent salaries, physician dual practices, absenteeism, and informal payments.
- Press governments and use development assistance to end hospital detention practices
- Engage communities in programmes and provide information on what will be given and to whom
- Evaluate programmes on the basis of health-outcomes and not on disbursement level or speed
- Engage in civic education to inform communities on structure and organisation of health-care systems and what an individual's rights are

UN Treaty Monitoring Bodies and the UN Special Rapporteur*:

- Acknowledge that hospital detention practices violate the UN Human Rights Declaration signed by African governments
- Investigate hospital detention practices and advise governments on how to stop these abuses

Governments in High-Income Countries:

- Stop businesses from high-income countries bribing African politicians and civil servants
- Stop banks in high-income countries from being safe havens for looted African funds
- Urge these banks to return monies stolen by African politicians and civil servants

African Governments:

- Strong leaders with high morality and integrity must set a good example for their subordinates
- Stop misappropriation of funds
- Address key components of health-care system:
  - Install monitoring systems for health budgets, personnel, and supplies
  - Make information on health-budgets, performance indicators, tender processes, conditions, and decisions freely available
  - Install and execute rewards for good performance and punishments for misconduct
  - Pay appropriate salaries to health-care providers in public hospitals
  - Install and execute legislation to make physician dual practices, absenteeism, and informal payments unlawful and punishable
  - Install independent monitoring bodies to ascertain that physician dual practices, absenteeism, and informal payments do not continue
- Install and execute legislation to make hospital detention practices unlawful and punishable.
- Install independent monitoring bodies to ascertain that the detention practices do not continue
- Install whistle-blower protection and independent anti-corruption institutions

Public Hospitals:

- Strong leaders with high morality and integrity must set a good example for their subordinates
- Stop misappropriation of funds
- Address key components of health-care systems:
  - Install monitoring systems for health-budgets, personnel and supplies
  - Introduce codes of conduct through continuous training
  - Install and execute rewards for good performance and punishments for misconduct
  - Obligate health-care providers to work full-time in public hospitals
  - Install and execute punishment for physician dual practices, absenteeism, informal payments
- Liberate all detained patients in public hospitals and stop hospital detention practices

*UN special rapporteur is an independent expert with mandates to investigate, report, and advise on human rights from a thematic or country-specific perspective

African leaders of high morality and integrity, serving as role models for subordinates, are the main prerequisite to fight corruption. Corrupt leaders and governments cannot be expected to take the initiative to wipe out corruption; however, international financial institutions, health organisations, and donors can influence African health policies with

funding, advice, and by applying their power within the health-care sector. Panel 3 shows recommendations for combined preventative measures to address corruption in health-care systems.[1,6] Monitoring systems, severe punishment for corruptors, rewards for good performance, and decent salaries must be installed in these corrupt health-care systems. Because access and quality of medical and cancer care for patients on low incomes and in public hospitals is impossible without experienced health-care providers, an essential step is needed to deal with this issue. Physician dual practices, absenteeism, and informal payments lead to medical neglect of patients on low incomes in public hospitals and needs to cease. Corrupt structure of health-care systems must be addressed to improve health and cancer care for patients in Africa.[13]

SEARCH STRATEGY AND SELECTION CRITERIA

We searched Pubmed and Google for relevant publications (January 1990 to February 2015) with the search terms “corruption” and “low-income countries” or “Africa”. Separate searches with these terms were complemented by those with terms related to the themes in the manuscript, such as “cancer” or “ethics”. Searches were supplemented by authors’ personal bibliographies. Only books, reports and articles published in English were included.

CONTRIBUTORS

SM searched the databases and wrote the first draft. FN, GO and SS included local perspectives. MNS, ES and GK redrafted the Personal View. All authors approved the final submitted version.

CONFLICTS OF INTEREST

We declare no competing interests.

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CHAPTER 9

FACTORS INFLUENCING TIME TO DIAGNOSIS AND TREATMENT AMONG PEDIATRIC ONCOLOGY PATIENTS IN KENYA[§§]

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ABSTRACT

Early diagnosis and start of treatment are fundamental goals in cancer care. This study determines the time lag and the factors that influence the time to diagnosis and start of treatment. Study participants were parents of childhood cancer patients diagnosed between August 2013 and July 2014 in a hospital in Kenya. Patient, physician, diagnosis, treatment, health care system, and total delay were explored using a questionnaire. Demographic and medical data were collected from the patients' medical records. Parents of 99 childhood cancer patients were interviewed (response rate: 80%). Median total delay was 102 (9–1021) days. Median patient delay (4 days) was significantly shorter than health care system delay (median 87 days;P < .001). Diagnosis delay (median 94 days) was significantly longer than treatment delay (median 6 days; P < .001). days. Lack of health insurance at diagnosis and use of alternative medicine before attending conventional health services were associated with a significantly longer patient delay (P = .041 and P = .017, respectively). The type of cancer had a significant effect on treatment delay (P = .020). The type of health facility attended affected only patient delay (P = .03). Gender, age at diagnosis, stage of disease, parents' education level or income, and distance from hospital did not have a significant effect on the length of any type of delay. Training on childhood cancer should be included in the curricula for medical training institutes. In-service workshops should be held for the health workers already working. Families must be obligated to get health insurance. Families should be encourage to attend conventional health facilities and informed on symptoms of cancer through mass media.

Abbreviations: *MTRH - Moi Teaching and Referral Hospital; NHIF - NationalHospital Insurance Fund*

INTRODUCTION

Low and middle-income countries bear the greater burden of childhood malignancies as compared to high-income countries. Of the annual 200,000 cancer cases that occur worldwide in children less than 15 years, about 70-80% are found in low and middle-income countries.[1-4]

Survival rates in high-income countries are up to 80%, while most countries in Africa have survival rates less than 30%.[5-7] This scenario has been attributed to many factors including difficulties in accessing hospital, paucity of trained personnel, lack of investigational and treatment capabilities as well as late presentation.[1,2,6,7]

Early diagnosis of cancer is a fundamental goal in cancer care because it gives opportunity for timely initiation of appropriate treatment, while the disease is at its earliest stages. Early diagnosis and start of treatment may improve prognosis and allow cure to be achieved with minimal side-effects.[8]

Variations in the length of diagnosis and treatment delay may be due to differences in health-care systems as well as patient-related and cancer-related factors. Health-care system factors include access to services, knowledge of providers as well as availability of diagnostic and treatment capabilities. Patient-related factors include age, sex and socio-economic background of the child, while cancer-related factors are mainly related to its clinical presentation and progression.[8,9]

The main purpose of this paper was to assess the various types of delay's seen among pediatric oncology patients at an academic hospital and to determine the factors that influence the time to diagnosis and start of treatment.

METHODS

Setting

Kenya is a low-income country in East-Africa. In 2014 Kenya had an estimated population of 45 million people of which 42% was aged between 0-14 years. Half of all Kenyan citizens live below the poverty line .[10,11]

The health system in Kenya is composed of government-owned and private health facilities. These facilities are organized in three levels; primary, secondary, tertiary**.** Primary health facilities include dispensaries, health-centers and private clinics and are mainly involved in health promotion and prevention and do not have admission facilities.

Secondary facilities include mission, private and district hospitals and are able to offer a wide variety of general and some specialized outpatient and inpatient care. Tertiary hospitals are the national referral hospitals and provide sub-specialized services. The majority of population accesses health care by paying out of their pockets.[12] Health-insurance is provided through private entities or through government-owned National Hospital Insurance Fund (NHIF). All persons working in the formal sector contribute to NHIF while those in the informal sector can join voluntarily at a cost of about 25 US dollars per year which covers inpatient care for the nuclear family in government-owned facilities.[13]

The study was conducted at Moi Teaching and Referral Hospital (MTRH) in Eldoret, Western Kenya. MTRH has a service area of 16-18 million people, which is about 40-45% of all inhabitants of Kenya. Although an estimated 700 childhood cancer patients under 15 years of age are expected in the service area of MTRH, only 100-110 children are annually diagnosed with cancer.[14]MTRH has a bed capacity of 700 patients of which 72 beds are located on the pediatric ward. Twelve of the 72 beds are reserved for oncology patients.

Study Design

This cross-sectional study was conducted using a semi-structured questionnaire. The focus was to assess the various types of delay among pediatric oncology patients seen at MTRH and to determine the factors that influence the time to diagnosis and start of treatment. Participants were parents of childhood cancer patients who were newly diagnosed between August 2013 and July 2014. We interviewed parents of all consecutive patients.

By definition, “patient delay” refers to time from onset of symptoms to first time patient has contact with conventional health-care provider regarding symptoms attributable to cancer. “Health-care system delay” refers to time from first presentation to health-care provider to initiation of treatment. “Diagnosis delay” represents time from onset of symptoms to time the diagnosis of cancer is confirmed. “Treatment delay” refers to time from confirmation of diagnosis to start of treatment. “Physician delay” refers to time from first contact with health-care provider to confirmation of diagnosis. “Total delay” refers to time from onset of symptoms to initiation of therapy (Figure1).[8]

Parents were asked when symptoms started and on which date they attended the first health-care provider. If parents could not recall the exact date of onset of symptoms and/or date of first contact with health-care provider, preconceived categories were used: early-mid-end of the month. During analysis we transformed these categories into day 5 – day 15 – day 25 (respectively) of the month.

The questionnaire contained open and structured questions that parents could evaluate on two to five-point rating scales. The items in the questionnaire had been derived from extensive literature studies. Questionnaire was pilot-tested for its content, clarity and cultural sensitivities on parents of 5 children and revised accordingly. Demographic and medical data was collected from medical records of childhood cancer patients: diagnosis, date of diagnosis, age at diagnosis, stage of disease and date of start treatment. Respondents rendered informed consent. Anonymity and confidentiality were guaranteed. Study was approved by Research Ethics Committee of MTRH.

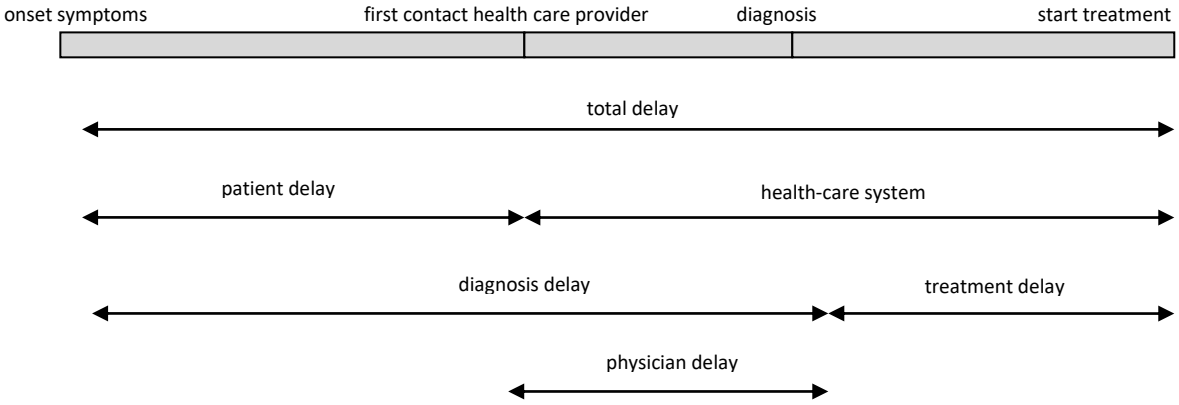

Figure 1. Types of delay

Data Analysis

Data management and analysis were executed by using SPSS. For each variable frequency distribution, median, means and standard deviations were calculated. Kruskal-Wallis test and Mann-Whitney test were used to compare time lag between different categorical variables. To compare paired time lag between patient delay and health-care system delay and between diagnosis delay and treatment delay, Wilcoxon Signed-Rank test was used. Statistical significance was set at $p<0.05$.

RESULTS

Demographic Characteristics

Between August 2013 and July 2014, 123 children were newly diagnosed with a malignancy. Caretakers of 99 children (response rate 80%) were interviewed. Parents of 21 patients (17%) were not interviewed for different reasons:patient deceased before interview could take place (52%), abandonment of treatment (24%), language barrier as parents spoke a rare dialect (14%), refusal to participate (10%). Three patients (2%) had to be excluded from analysis because parents could not recall when symptoms started or what the date was of first health facility visit. Respondents included following caretakers: mothers (56%), fathers (21%), uncles/aunts (10%), grandparents (6%), siblings (4%), both parents (2%), guardian (1%). Table 1 presents parents' characteristics.

Of 99 children, 67% were male. Patients' age at diagnosis was a mean of 6.5 years (SD=3.8) and median 5.7 years. Hematological tumors contributed for 54% and solid tumors for 46% of all cases. There were no significant differences in patients' age at diagnosis, gender or type of cancer between respondents (n=99) and non-respondents (n=24).

Table 1Parent characteristics (n=99)

Parent characteristics		
Age in years	**Mother (n=89)**	**Father (n=76)** -
mean ± SD	32.4 ± 7.6	37.9 ± 9.4
- median (range)	31 (19-56)	37 (23-77)
Occupation	**Mother (n=96)**	**Father (n=91)**
- Housewife	31 (32%)	0 (0%)
- Farmer	28 (29%)	31 (34%)
- Regular job	23 (24%)	37 (41%)
- Casual labourer	6 (6%)	18 (20%)
- Unemployed	7 (7%)	4 (4%)
- Student	1 (1%)	1 (1%)
Religion	**Mother (n=96)**	**Father (n=93)**
- Christian	95 (99%)	88 (95%)
- Muslim	1 (1%)	1 (1%)
- No religion	0 (0%)	4 (4%)
Tribe	**Mother (n=97)**	**Father (n=93)**
- Luhya	34 (35%)	32 (34%)
- Kalenjin	32 (33%)	33 (36%)
- Luo	13 (13%)	12 (13%)
- Kisii	5 (5%)	5 (5%)
- Pokot	4 (4%)	4 (4%)
- Turkana	4 (4%)	3 (3%)
- Gikuyu	2 (2%)	2 (2%)
- Meru	1 (1%)	1 (1%)
- Maasai	1 (1%)	1 (1%)
- Teso	1 (1%)	0 (0%)
Marital status (n=98)		
- Married	73 (75%)	
- Widowed	13 (13%)	
- Separated	5 (5%)	
- Single	4 (4%)	
- Living together	2 (2%)	
- Both parents deceased	1 (1%)	
Number of children		
- mean ± SD	4.3 ± 2.5	
- median (range)	4 (1-13)	

Various Types of Delay

Table 2 presents socio-demographic and clinical characteristics and the various types of delay. Some parents could not tell the exact date of onset of symptoms (66%) or the exact date of first contact with a conventional health-care provider (55%) and therefore used the preconceived categories. Paired comparison of patient delay and health-care system delay showed the latter to be significantly longer (P<0.001). Paired comparison of diagnosis delay and treatment delay showed the first to be significantly longer (P<0.001).

Onset of Symptoms

Children suffered from following major symptoms before seeking medical care: swelling (51%), pain (35%), fever (26%), vomiting (15%), loss of weight (13%), loss of appetite (10%), fatigue (8%), weakness (7%). After noticing these symptoms parents sought advice from relatives and friends (50%), and decided to first wait and watch (36%). Table 2 shows patient delay.

Distance and Transportation to Hospital

Of all participants, 76% lived more than 100 km from MTRH. Travel time to MTRH was: <1 hour (4%), 1-3 hours (41%) and >3 hours (55%). Mode of transportation to reach MTRH is: public transport (94%), motorbike (23%), walking (18%), private car (5%), renting motorbike (4%), ambulance (2%) and renting vehicle (1%). Note that some respondents reported a combination of transportation modes. Travelling to hospital is considered to be: expensive (81%), time consuming (74%) and difficult (50%). No significant difference was found between distance to MTRH and any type of delay (Table 2).

Financial Situation

Minority (38%) of households have regular income. Main economic provider is: father (48%), both parents (25%), mother (20%), grandparents (5%), aunt (1%) and relatives (1%). Families lived either below (37%) or above (63%) poverty line of 1.25 USD per day. Table 2 illustrates that no statistically significant difference in all types of delay was found between families living below or above poverty line. When coming to MTRH, 71 families (72%) lose daily wages and 40 families (41%) lose profits from farming the land.

Health-Insurance

Most families (67%) did not have health-insurance before onset of illness and 64% did not have insurance when they first came to MTRH. Having health-insurance at diagnosis resulted in a significantly less patient delay (P=0.049) as shown in Table 2.

Social Support for Alternative and Conventional Treatment

Parents (58%) were advised to seek alternative treatment for disease in their child by: grandparents (53%), village community (51%), friends (47%), relatives (42%), spouse (26%), religious community (16%), medical personnel (7%) and clan elder (2%). Parents (34%) were advised not to attend public hospitals by: village community (50%), relatives (44%), friends (41%), grandparents (32%), spouse (24%), religious community (9%).

Table 2. Socio-demographic and clinical characteristics and types of delay (in days)

Socio-demographic and clinical characteristics:	No. patients (%)	Patient delay Mean (SD)	Median	range	P	Physician delay Mean (SD)	Median	range	P	Diagnosis delay Mean (SD)	Median	range	P	Treatment delay Mean (SD)	Median	range	P	Health-care system delay Mean (SD)	Median	range	P	Total delay Mean (SD)	Median	range	P
All patients	99 (100%)	25.1 (53.5)	4,0	(0-355)		123.6 (162.0)	75,0	(3-1017)		148.7 (172.1)	94,0	(6-1020)		10.8 (18.8)	6,0	(0-145)		134.4 (167.4)	87,0	(7-1018)		159.6 (178.3)	102,0	(9-1021)	
Gender																									
Male	66 (67%)	23.0 (52.0)	3,0	(0-355)	ns*	118.3 (155.3)	69,0	(4-980)	ns*	141.3 (162.7)	90,0	(6-981)	ns*	11.1 (20.9)	5,0	(0-145)	ns*	129.5 (163.7)	78,0	(7-986)	ns*	152.5 (171.6)	95,5	(9-987)	ns*
Female	33 (33%)	29.4 (56.9)	9,0	(0-243)		134.1 (176.7)	97,0	(3-1017)		163.4 (191.2)	121,0	(14-1020)		10.3 (14.0)	7,0	(0-69)		144.3 (176.6)	112,0	(15-1038)		173.7 (193.0)	125,0	(18-1021)	
Age																									
≤ 5 years	52 (53%)	26.9 (57.9)	4,0	(0-355)	ns**	102.8 (114.0)	73,5	(3-621)	ns**	129.7 (135.3)	92,5	(6-753)	ns**	10.0 (21.5)	4,0	(0-145)	ns**	112.8 (127.7)	78,0	(11-766)	ns**	139.6 (148.4)	95,5	(13-898)	ns**
6-10 years	25 (25%)	20.6 (43.7)	3,0	(0-212)		163.6 (206.2)	81,0	(5-1017)		184.2 (209.4)	128,0	(7-1020)		11.4 (16.5)	6,0	(0-69)		175.0 (205.8)	95,0	(7-1018)		195.6 (211.6)	153,0	(9-1021)	
≥ 10 years	22 (22%)	26.0 (54.7)	5,0	(0-243)		127.3 (198.3)	85,5	(7-980)		153.3 (202.9)	95,0	(39-981)		12.3 (14.4)	7,5	(0-56)		139.6 (198.8)	96,5	(10-986)		165.6 (202.9)	107,5	(43-987)	
Stage at diagnosis																									
Low (stage I, II, intraocular)	13 (32%)	12.7 (17.4)	3,0	(0-61)	ns*	92.8 (91.7)	61,0	(20-360)	ns*	105.5 (90.0)	91,0	(23-362)	ns*	6.5 (7.9)	3,0	(0-28)	ns*	99.3 (91.5)	71,0	(21-360)	ns*	112.0 (90.9)	97,0	(24-362)	ns*
High (stage III, IV, extraocular)	28 (68%)	35.4 (62.5)	5,5	(0-243)		180.1 (246.6)	97,0	(12-1017)		215.5 (252.3)	133,5	(37-1020)		10.6 (16.1)	5,0	(0-69)		190.8 (245.5)	114,5	(19-1018)		226.2 (252.7)	137,0	(39-1021)	
Diagnosis																									
Nephroblastoma	21 (21%)	20.1 (40.0)	3,0	(0-153)	ns**	106.3 (83.8)	97,0	(10-360)	ns**	126.4 (80.8)	133,0	(12-362)	ns**	4.5 (9.5)	3,0	(0-45)	0.020**	110.8 (84.0)	108,0	(11-360)	ns**	131.0 (82.1)	134,0	(13-362)	ns**
Non-Hodgkin lymphoma	19 (19%)	13.8 (17.4)	3,0	(0-56)		72.9 (75.7)	49,0	(9-307)		86.7 (79.5)	71,0	(11-338)		12.1 (14.2)	10,0	(0-53)		85.1 (77.8)	66,0	(16-318)		98.8 (80.6)	73,0	(18-349)	
Acute lymphoblastic leukemia	15 (15%)	9.0 (10.6)	7,0	(0-41)		140.3 (110.5)	97,0	(3-305)		149.3 (108.0)	138,0	(14-306)		8.1 (6.7)	7,0	(0-24)		148.5 (111.5)	112,0	(15-329)		157.5 (109.3)	153,0	(26-329)	
Rhabdomyosarcoma	10 (10%)	34.3 (39.3)	18,0	(1-132)		147.8 (181.3)	77,5	(24-621)		182.1 (212.2)	116,5	(43-753)		28.2 (43.4)	15,0	(0-145)		176.0 (223.2)	89,0	(34-766)		210.3 (254.2)	124,5	(58-898)	
Hodgkin's Lymphoma	10 (10%)	55.0 (92.9)	5,5	(1-243)		271.1 (387.3)	82,0	(32-1017)		326.1 (381.9)	114,0	(39-1020)		14.9 (20.8)	7,5	(0-69)		286.0 (383.6)	99,5	(40-1018)		341.0 (380.8)	131,5	(43-1021)	
Acute myeloid leukemia	9 (9%)	19.6 (34.1)	2,0	(0-103)		79.6 (99.1)	73,0	(4-318)		99.1 (103.0)	81,0	(6-339)		6.9 (4.6)	8,0	(0-14)		86.4 (98.1)	87,0	(7-318)		106.0 (101.7)	89,0	(9-339)	
Retinoblastoma	5 (5%)	106.2 (146.5)	30,0	(3-355)		139.4 (138.9)	109,0	(22-368)		245.6 (180.0)	161,0	(61-490)		4.8 (6.4)	2,0	(0-15)		144.2 (140.0)	116,0	(22-370)		250.4 (178.0)	176,0	(61-492)	
Neuroblastoma	3 (3%)	13.7 (23.7)	0,0	(0-41)		114.7 (107.8)	82,0	(27-235)		128.3 (130.8)	82,0	(27-276)		1.0 (1.0)	1,0	(0-2)		115.7 (107.5)	82,0	(29-236)		129.3 (130.6)	82,0	(29-277)	
Kaposi sarcoma	2 (2%)	7.0 (5.7)	7,0	(3-11)		115.0 (86.3)	115,0	(54-176)		122.0 (80.6)	122,0	(65-179)		39.5 (23.3)	39,5	(23-56)		154.5 (109.6)	154,5	(77-232)		161.5 (103.9)	161,5	(88-235)	
Osteogenic sarcoma	1 (1%)	0,0	0,0	(0-0)		22,0	22,0	(22-22)		22,0	22,0	(22-22)		0,0	0,0	(0-0)		22,0	22,0	(22-22)		22,0	22,0	(22-22)	
Hepatoblastoma	1 (1%)	4,0	4,0	(4-4)		65,0	65,0	(65-65)		69,0	69,0	(69-69)		2,0	2,0	(2-2)		67,0	67,0	(67-67)		71,0	71,0	(71-71)	
Nasopharyngeal carcinoma	1 (1%)	6,0	6,0	(6-6)		129,0	129,0	(129-129)		135,0	135,0	(135-135)		7,0	7,0	(7-7)		136,0	136,0	(136-136)		142,0	142,0	(142-142)	
Teratoma, germ cell tumor	1 (1%)	1,0	1,0	(1-1)		32,0	32,0	(32-32)		33,0	33,0	(33-33)		17,0	17,0	(17-17)		49,0	49,0	(49-49)		50,0	50,0	(50-50)	
Seminoma	1 (1%)	1,0	1,0	(1-1)		88,0	88,0	(88-88)		89,0	89,0	(89-89)		2,0	2,0	(2-2)		90,0	90,0	(90-90)		91,0	91,0	(91-91)	
Income																									
< Poverty line of 1.25 USD/ day	28 (37%)	23.6 (49.2)	5,0	(0-243)	ns*	98.6 (94.5)	58,5	(3-360)	ns*	122.2 (108.8)	91,5	(12-400)	ns*	11.1 (14.0)	7,5	(0-53)	ns*	109.7 (93.6)	67,0	(11-360)	ns*	133.3 (107.4)	92,5	(9-362)	ns*
> Poverty line of 1.25 USD/ day	47 (63%)	22.6 (58.0)	3,0	(0-355)		111.1 (112.9)	75,0	(9-621)		133.7 (130.2)	91,0	(11-753)		12.1 (23.1)	6,0	(0-145)		123.2 (129.8)	82,0	(16-766)		145.8 (146.8)	97,0	(13-1021)	
Health-insurance at diagnosis																									
Yes	35 (36%)	11.9 (23.6)	3,0	(0-132)	0.049*	129.7 (128.7)	75,0	(12-621)	ns*	141.6 (141.6)	91,0	(22-753)	ns*	12.8 (25.2)	6,0	(0-145)	ns*	142.5 (146.7)	81,0	(22-766)	ns*	154.5 (161.1)	97,0	(22-898)	ns*
No	63 (64%)	32.8 (63.6)	7,0	(0-355)		122.1 (179.3)	81,0	(3-1017)		154.9 (188.2)	108,0	(6-1020)		9.9 (14.3)	6,0	(0-69)		132.0 (179.4)	89,0	(10-1018)		164.8 (188.7)	112,0	(13-1021)	
Distance home-MTRH																									
≤ 50 km	11 (11%)	5.1 (9.1)	2,0	(0-31)	ns**	62.2 (46.0)	61,0	(3-134)	ns**	67.3 (45.2)	88,0	(14-135)	ns**	9.0 (15.1)	4,0	(0-53)	ns**	71.2 (42.6)	71,0	(15-139)	ns**	76.3 (42.1)	89,0	(18-140)	ns**
50-100 km	13 (13%)	27.5 (56.8)	10,0	(1-212)		93.3 (90.7)	75,0	(4-318)		120.8 (123.3)	90,0	(6-418)		12.2 (22.7)	4,0	(0-69)		105.5 (102.5)	80,0	(12-318)		133.0 (139.0)	90,0	(14-487)	
≥ 100 km	75 (76%)	27.6 (56.5)	6,0	(0-355)		137.8 (179.5)	80,0	(5-1017)		165.5 (187.2)	128,0	(7-1020)		10.9 (18.8)	7,0	(0-145)		148.7 (184.9)	88,0	(7-1018)		176.4 (193.1)	134,0	(9-1021)	
Father's education																									
Low (no education, primary school)	50 (54%)	26.1 (55.9)	5,5	(0-355)	ns*	139.7 (207.5)	85,0	(4-1017)	ns*	165.8 (212.4)	109,0	(6-1020)	ns*	13.3 (23.7)	7,0	(0-145)	ns*	153.0 (214.8)	89,5	(10-1018)	ns*	179.1 (220.6)	115,0	(13-1021)	ns*
High (high school, tertiary institute)	43 (46%)	22.0 (46.2)	3,0	(0-243)		109.7 (98.1)	74,0	(3-368)		131.7 (114.2)	91,0	(14-490)		7.0 (7.5)	5,0	(0-28)		116.7 (97.3)	80,0	(15-370)		138.7 (113.0)	97,0	(22-492)	
Mother's education																									
Low (no education, primary school)	67 (69%)	29.4 (60.2)	7,0	(0-355)	ns*	127.6 (183.1)	75,0	(3-1017)	ns*	157.0 (194.0)	92,0	(6-1020)	ns*	11.1 (20.9)	6,0	(0-145)	ns*	138.7 (189.1)	82,0	(10-1018)	ns*	168.0 (201.3)	100,0	(13-1021)	ns*
High (high school, tertiary institute)	30 (31%)	17.0 (35.8)	3,0	(0-153)		120.2 (108.6)	86,5	(9-368)		137.2 (115.3)	114,5	(11-490)		11 (13.9)	6,0	(0-56)		131.2 (111.9)	100,5	(18-370)		148.2 (118.0)	118,5	(21-492)	
Used alternative treatment																									
Yes	58 (59%)	31.2 (51.5)	9,5	(0-243)	0.017*	125.7 (117.9)	88,5	(3-621)	ns*	156.9 (137.5)	109,0	(14-753)	0.030*	11.9 (22.8)	4,0	(0-145)	ns*	137.6 (129.4)	93,0	(10-766)	ns*	168.8 (150.2)	115,0	(24-898)	0.033*
No	41 (41%)	16.5 (55.7)	3,0	(0-355)		120.6 (210.9)	67,0	(4-1017)		137.1 (212.9)	80,0	(6-1020)		9.4 (11.0)	7,0	(0-56)		130.0 (211.5)	75,0	(7-1018)		146.4 (213.2)	82,0	(9-1021)	
First attended health facility																									
Primary care level	59 (60%)	15.0 (37.6)	3,0	(0-243)	0.032**	101.3 (79.7)	88,0	(5-360)	ns**	116.3 (88.6)	90,0	(7-400)	ns**	9.5 (12.8)	7,0	(0-56)	ns**	110.8 (82.4)	89,0	(7-360)	ns**	125.8 (90.4)	91,0	(9-401)	ns**
Secondary care level	38 (38%)	41.3 (70.0)	13,5	(0-355)		155.1 (238.2)	67,0	(3-1017)		196.4 (247.7)	106,5	(6-1020)		12.6 (25.9)	4,0	(0-145)		167.7 (245.8)	78,0	(10-1018)		209.0 (257.3)	110,5	(14-1021)	
Tertiary care level	2 (2%)	15.5 (21.9)	15,5	(0-31)		183.0 (172.5)	183,0	(61-305)		198.5 (150.6)	198,5	(92-305)		17.0 (9.9)	17,0	(10-24)		200.0 (182.4)	200,0	(71-329)		215.5 (160.5)	215,5	(102-329)	

*Mann-Whitney U test

**Kruskal-Wallis test

Alternative Treatment

After noticing symptoms of the child, 58 parents (59%) sought alternative treatment for their children: praying ceremonies (41%), visiting herbalist (36%), special food intake (11%), and attending traditional healer (3%). Reasons for using alternative treatment are illustrated in Table 3. Use of alternative medicine resulted in significantly longer patient delay (P=0.017), diagnosis delay (P=0.030) and total delay (P=0.033).

Table 3. Reasons for using alternative treatment according to parents (n=58)

Reasons for alternative treatment:	N	(%)
Helpful	53	91%
Hope for improvement of child's condition	52	90%
Hope for cure	49	85%
Recommended by others	36	62%
Other patients look healthy after taking it	29	50%
Certainty of cure	28	48%
Easy accessible	28	48%
At short distance available	24	41%
Child will not be detained in public hospital *	9	36%
Child can stay inside the family	19	33%
No side-effects	17	29%
Cheap	17	29%
No discomfort	14	24%
Conventional treatment has no certainty of cure	10	17%
No health-insurance	9	16%
Fear of surgery in public hospital	8	14%

* 25 parents were aware of the procedure of detaining children in hospital over unpaid medical bills (hospital detention practices).9 of these parents (36%) gave this reason for using alternative treatment.

First Contact with Conventional Health-Care Facilities

Patients' first contact with a health-care facility was at primary- (60%), secondary- (38%) and tertiary-care level (2%). During this first contact, patients were helped by doctor (68%) or nurse (32%). Most children (69%) were initially treated for one or more other illnesses: e.g. malaria (34%), infection (25%), pain (15%) and anemia (7%).

Cancer Education during First Contact with Conventional Health-Care Facilities

During first contact with conventional health-care provider cancer was mentioned as possible diagnosis to 12 parents (12%). This health-care provider subsequently encouraged parents to seek conventional cancer treatment (92%) and discouraged complementary alternative treatment (42%). Curability of cancer was discussed with 10 of these parents (83%): 90% were told that cancer is curable and 10% that cancer is

incurable. Affordability of cancer treatment was discussed with 4 of these parents (33%): 3 (75%) were told cancer treatment is not affordable and 1 (25%) that cancer treatment is affordable. During first contact with conventional health-care provider 20% of all parents were advised to enroll in NHIF.

Total Number of Visits to Conventional Health-Care Facilities

Table 4 illustrates type of health-care facilities patients attended prior to receiving cancer treatment at MTRH. Total number of visits to other conventional health-care facilities prior to attending MTRH ranged from 1 to 9 visits with a mean of 3 visits (SD=1.5), and median of 3 visits. The first health facility attended significantly affected patient delay (P=0.03), but not other forms of delay.

Table 4. Type of conventional health-care facilities patients attended prior to cancer treatment at MTRH (n=99)

Health-care facilities attended prior to cancer treatment	**Visit 1**	**Visit 2**	**Visit 3**	**Visit 4**	**Visit 5**	**Visit 6**	**Visit 7**	**Visit 8**	**Visit 9**	**Visit 10**
Primary care level*	59 (60%)	30 (30%)	13 (13%)	6 (6%)	3 (3%)	2 (2%)	2 (2%)	0 (0%)	0 (0%)	0 (0%)
Secondary care level**	38 (38%)	54 (55%)	43 (43%)	29 (29%)	9 (9%)	2 (2%)	0 (0%)	2 (2%)	1 (1%)	0 (0%)
Tertiary care level ***	2 (2%)	0 (0%)	0 (0%)	1 (1%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
SUBTOTAL	**99 (100%)**	**84 (85%)**	**56 (57%)**	**36 (36%)**	**12 (12%)**	**4 (4%)**	**2 (2%)**	**2 (2%)**	**1 (1%)**	**0 (0%)**
Cancer treatment at MTRH										
Tertiary care level***	**0 (0%)**	**15 (15%)**	**43 (43%)**	**63 (64%)**	**87 (88%)**	**95 (96%)**	**97 (98%)**	**97 (98%)**	**98 (99%)**	**99 (100%)**
TOTAL	99 (100%)	99 (100%)	99 (100%)	99 (100%)	99 (100%)	99 (100%)	99 (100%)	99 (100%)	99 (100%)	99 (100%)

* dispensary, community health-center, sub-district center, private practice
**district hospital, mission hospital, private hospital
***National hospital

Health Beliefs

In total 81 parents (82%) had heard of cancer before their child had been diagnosed with cancer. These parents perceived cancer to be curable (61%), incurable (37%) or were uncertain (3%). Prior to coming to MTRH

conventional cancer treatment was thought to be unaffordable (78%), affordable (11%), or parents were unsure (11%). Use of surgery in cancer treatment was believed to be: helpful (96%), necessary (83%), frightening (62%), causing death (46%) and spreading cancer (32%).

Reasons for Delay in Coming to MTRH

Many families (97%) encountered difficulties coming to MTRH for the first time. Table 5 illustrates reasons for delay in attending MTRH. Before coming to MTRH, 25 families (25%) had heard of not being allowed to take your child home in public hospitals in case families are unable to pay their medical bills (hospital detention practices). Ten of these families (40%) delayed coming to MTRH because of this. Of all 99 parents, 86% stated that parents would come sooner to public hospitals if children were not detained over unpaid medical bills.

Table 5. Reasons for delay in coming to MTRH for the first time according to

Reasons for delay in attending MTRH	N	(%)
Travel costs	76	79%
Hospital costs	66	69%
Distance from clinic	55	57%
Loss of daily wages	39	41%
Detention of child in hospital *	10	40%
Poor transport facilities	35	37%
Nobody to look for other children	33	34%
No health-insurance	24	25%
Nobody to look for the land	20	21%
Going to work	19	20%
Too busy	14	14%
Reputation of long delays in public hospital	13	15%
Child appears ill	12	13%
Time clinic appointment is inconvenient	12	13%
Not satisfied with provided care in the past	10	10%
Hospital procedure to clear bill	10	10%
Disease of my child may not be curable	9	9%
Fear of cancer treatment	9	9%
Fear of surgery	7	7%
Side-effects of cancer treatment	6	6%
Reputation of corruption in public hospitals	5	5%
Do not see benefit of hospital visit	2	2%

* 25 parents were aware of the procedure of detaining children in hospital over unpaid medical bills (hospital detention practices).10 of these parents (40%) gave this reason for delay in coming to MTRH for the first time.

First Contact with MTRH

Before attending MTRH for the first time, 23 children (23%) had already been diagnosed with cancer at primary- (9%), secondary- (83%) and tertiary-care level (9%). The first department at MTRH which parents attended was: sick child clinic (77%), eye clinic (9%), hemato-oncology clinic (7%), ear nose and throat clinic (3%), private wing outpatient clinic (2%), casualty clinic (2%) and dental clinic (1%).Most children (99%) were immediately admitted and investigated for cancer.

DISCUSSION

This study demonstrates that diagnosis and treatment delay is a major issue. Median total delay was 102 days. Overall patient delay (median 4 days) was considerably shorter than health-care system delay (median 87 days). Although the total delay figures are similar to findings in Nigeria where median total delay was 109 days, our figures are longer than what has been reported in other studies done in Africa. [15-18] A study done in Western Kenya and Uganda, specifically looking at Burkitt lymphoma, reported total delays of 12.1 and 12.9 weeks respectively. This is shorter than what we found though close to what we found in our Non-Hodgkin lymphoma patients who had a mean total delay of 73 days.[19] Similar studies in Egypt and South-Africa reported median total delays of 47 and 34 days respectively. The short total delay reported from South-Africa could be a reflection of the superior infrastructure and health-care system in the country and is similar to total delays found in high-income countries, such as Canada which also has a median total delay of 34 days.[15-18]

Health-care system delay in our study was significantly longer than patient delay. This is unlike what has been reported by the Nigerian study where patient delay was longer than health-care system delay as well as the Burkitt lymphoma study in Western Kenya. However the Egyptian and South-African study also demonstrated a longer health-care system delay.[15-19] This may mean that parents in our setting come to hospital relatively fast but a lot of delays occur in the health-care system. These could be because medical workers are not able to suspect and make the right diagnosis. It could also reflect complex referral systems aswell as unavailability and inefficiencies of equipment and personnel to make correct diagnosis. Dual physician practices and absenteeism could also be contributing factors. [20-21] Government should enforce policies to stop dual physician practices by raising government salaries and obligating doctors to work full-time in public hospitals.

Training on how to suspect and diagnose cancer among health-care workers could help to reduce the health-care system delay**.**

The treatment delay was a median of 6 days. This is similar to what was reported in Nigeria.[15] This delay could especially occur among patients who are diagnosed in other hospitals and are referred to MTRH for care. It could also happen as some families take time before reaching a decision on whether to start treatment for their children. Some patients may be quite sick and supportive measures are undertaken before their treatment is initiated. The lack of consistent availability of senior doctors also slows down the process as their opinion may be needed before treatment is started.[20-21]

This study did not find a significant difference in the delays between the two genders. The sex of the child has been found not to influence diagnosis delay in different studies. [16,17,23,24] This may imply that there are no differences in health-seeking behavior regardless of the gender of the child.

The longest total delay was for the age group 6-10 years though it was not significantly longer when compared to the other age groups. Those who were less than 5 years had the shortest delay which could be because the common tumors in this age group are aggressive and may lead to faster presentation. Most studies have reported the time lag to be longer for older children. However in Nigeria there were no differences among the age groups. [15,16,17]

Most common diagnosis in this series was nephroblastoma, followed by non-Hodgkin lymphoma and acute lymphoblastic leukemia. The type of cancer only significantly affected treatment delay. However, it is important to note that retinoblastoma patients had the longest median patient delay (30 days) as well as very long median physician delay (109 days). This could imply that signs and symptoms of retinoblastoma are not easily recognized by parents and health-care providers.

The Nigerian study found long patient and physician delays among retinoblastoma and Hodgkin lymphoma patients.[15] Hodgkin lymphoma commonly presents in an indolent manner with painless adenopathy which mimics tuberculosis of lymphatic system. Given the high prevalence of tuberculosis in Low income settings, most of these patients are likely to be treated with anti-tuberculosis medication and an alternative diagnosis is only sought when there is no response several months later.[25-26] However, our median patient and physician delays for

Hodgkin lymphoma patients were not extremely long compared to other types of cancers.

Treatment delay was longest for Kaposi's sarcoma, although one needs to acknowledge that there were only two patients. Most patients in this set-up have Human Immunodeficiency virus associated Kaposi sarcoma. Unless the disease is life threatening the specific treatment for Kaposi sarcoma is delayed and antiretrovirals are used to improve the patients' immunity and reduce the Kaposi sarcoma burden. This may lead to the long treatment delay documented here.[27]

The shortest total delays were among Non-Hodgkin lymphoma and acute myeloid leukemia patients. They also had shortest patient delays. This could be attributed to the nature of diseases whereby Non-Hodgkin lymphoma usually presents with rapidly enlarging mass and acute myeloid leukemia presents with significant bleeding. Other authors have reported a shorter total delay for acute leukemia compared to solid tumors.[21,22]

Only 33% of patients had health-insurance (NHIF) at time of onset of symptoms.[13] Having insurance resulted in significantly shorter patient delay compared to those without. This is one of the areas that the government and other stakeholders should focus on given that we have previously shown that having insurance also reduces risk of abandonment and improves survival. [28,29]

More than half of families reported use of alternative treatment before coming to MTRH. Use of alternative treatment resulted in significantly longer patient delay as well as diagnosis delay. Previous studies in this setting have shown that many families use complementary alternative medicine.[29] While parents had valid reasons for using alternative treatment it shows that time is lost before they seek care in a conventional health facility. More community education would alleviate this though the challenges associated with accessing health-care in Kenya need to be addressed as well. These include long distances to facilities, poor facilities as well as the negative perceptions about poor service provision from health-care workers.[31-32]

Parents' level of education did not have a significant effect on either patient or total delay. Other studies have given contrasting reports. In Egypt shorter total delay among parents with higher education level was reported.[17] Studies in Nigeria and South-Africa however showed that level of education has no effect on total delays. The level of income also

did not have an effect on the delays. Majority of families lived more than 100km from MTRH but this had no effect on either patient or total delays. The cost of travel to hospital would be expected to be an economic burden to most poor families. All these socio-economic factors are interrelated and did not have a significant effect on delay patterns.

Hospital detention practices are not known to the majority of parents prior to coming to MTRH. Among those who were aware 40% reported it as a reason to delay coming to hospital and 36% as a reason to seek alternative treatment. Hospital detention occurs when families are not allowed to take their child home after discharge due to failure to pay hospital bills. This has been shown to have negative consequences on the families and may influence their health-seeking behaviour. The families feel desperate, powerless and feel the hospital is like a prison. Families may avoid coming to the hospital when they are aware of the detention practices.[30,33,34] It may contribute to the lower reported than expected childhood cancer incidence (100-110 children versus 700 children) in the service area of MTRH. [14]

In conclusion we found that total delay is much longer than has been reported in most previous studies. The only factor that significantly affected total delay was use of alternative treatment. The health-care system delay was significantly longer than patient delay. Factors associated with long patient delay include: health-insurance at onset of diagnosis and use of alternative treatment. There were no factors that significantly affected physicians' delay as well as health-care system delay. Treatment delay was only significantly associated with the type of cancer.

This study had several limitations. There could have been a recall bias regarding the onset of symptoms and health facility attendance. Parents may also have been giving socially desirable answers as criticism is not encouraged in the Kenyan culture.[30]

Based on our study findings, we recommend that training on childhood cancer be incorporated into the curricula of medical training institutions. Workshops to sensitize those already working should be organized as well as presentations in scientific conferences of various cadres of health workers Sensitization of lay communities through mass media on common symptoms of cancer should be organized through the division of health promotion at the Ministry of Health. The public also needs to be encouraged to visit conventional health facilities first whenever their

children are unwell. The government should make it mandatory to register with NHIF when acquiring the national identity card at the age of 18 years as well as when children get their birth certificates.

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CHAPTER 10

WILMS' TUMOR TREATMENT OUTCOMES: PERSPECTIVES FROM A LOW-INCOME SETTING[***]

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ABSTRACT

Background: *Wilms' tumor is the commonest renal malignancy in childhood. Survival in high-income countries is about 90%, while in low-income countries it is less than 50%. This study assessed treatment outcomes of Wilms' tumor patients at a Kenyan academic hospital, and the influence of various socio-demographic and clinical characteristics on treatment outcomes.*

Methods: *This was a retrospective medical records review of all children diagnosed with Wilms' tumor between 2010 and 2012. Data on treatment outcomes and various socio-demographic and clinical characteristics was collected.*

Results: *Of all 39 Wilms' tumor patients, 41% had event-free survival, 31% abandoned treatment, 23% died, 5% had progressive or relapsed disease. Most patients presented at advanced stages: stage I (0%), stage II (7%), stage III (43%), stage IV (40%), stage V (10%). The most likely treatment outcome in patients with low (I-III) stage disease was event-free survival (67%), whereas in high (IV-V) stage disease it was death (40%).No death and progressive or relapsed disease occurred among patients with low stage disease.Their only reason for treatment failure was abandonment of treatment. Stage of disease significantly impacted treatment outcomes (P=0.014) and event-free survival estimates (P<0.001). Age at diagnosis, gender, duration of symptoms, distance to hospital, and health-insurance status did not statistically significantly influence treatment outcomes and event-free survival estimates. Living at shorter distance from MTRH and having health-insurance at diagnosis led to better chances of survival, but this did not reach statistical significance (P=0.063, P=0.358 respectively).*

Conclusion: *Survival of Wilms' tumor patients in Kenya is lower compared to high-income countries. Treatment abandonment is the most common cause of treatment failure. Stage of disease at diagnosis statistically significantly affects treatment outcomes and survival.*

Abbreviations: *SIOP - Society of International Paediatric Oncology; MTRH - Moi Teaching and Referral Hospital; NHIF - National Hospital Insurance Fund*

INTRODUCTION

Wilms' tumor is the most common primary renal malignancy in children. It accounts for 5% of childhood malignancies.(1) It is thought to arise from nephrogenic rests which are foci of persistent metanephrenic cells.(2) The survival rates have improved from 20% in the 1960s to about 90% currently in high-income countries, while middle-income countries have survival of about 80%.(2,3) This has been achieved through cooperative study groups as well as use of multimodal approaches to therapy. The two main study groups that have been involved are the National Wilms' Tumor Study Group and the International Society of Paediatric Oncology (SIOP).(2,4,5)

Low-income countries however have survival rates between 20%-50%.(1,2,3) The reasons for the low survival in low-income countries include limited access to proper medical care as a result of lack of facilities for treatment, shortage of personnel, long distances to treatment centers, poor infrastructure and limited public transport facilities. These factors lead to late presentation which also impacts the outcomes. Other contributors to the low survival include lack of health-insurance, abandonment of treatment and lack of multidisciplinary approach to the management of patients. Treatment includes surgery and chemotherapy, as well as radiotherapy for metastatic disease.(2,3,5)

The aim of this study was to assess the treatment outcomes of children presenting with Wilms' tumor at a Kenyan academic hospital, and evaluate the influence of various socio-demographic and clinical characteristics (age at diagnosis, gender, duration of symptoms, stage of disease, distance to hospital, and health-insurance status) on treatment outcomes.

METHODS

Setting

Kenya is situated in East Africa and is a low-income country with a population of about 43 million people.(6) Most of the population (45%) lives below the poverty line.(7) This study was carried out at Moi Teaching and Referral Hospital (MTRH) which is an academic hospital in Eldoret, a town 300 kilometers Northwest of the capital city Nairobi. The hospital has a capacity of about 800 beds, including 72 beds in the pediatric ward of which 12 are dedicated to pediatric oncology.(8) About 120 pediatric oncology patients are seen in the hospital every year as opposed to the expected number of 700 patients.(8) One pediatrician is involved in the care of oncology patients. Two pediatric surgeons are

involved in the operative aspects. There is no radiotherapy facility in Eldoret and the patients who require it are referred to a center in Nairobi. Families pay for their hospital bills through health-insurance or out of pocket payments. Only about 10% of the Kenyan population however have health-insurance which is provided by the government-owned and controlled National Hospital Insurance Fund (NHIF) or through private insurance companies. Kenyan citizens can enroll with NHIF and pay a set monthly fee. Payments are dependent on the level of income for those who are in formal employment, while those who are self-employed or are casual workers pay a monthly fee of about 1.2 US dollars. NHIF provides cover for inpatient care for the entire family in government-owned health facilities.(9,10)

Wilms' tumor patients are treated with a protocol which is modelled on the SIOP approach. Treatment is started after imaging by a CT-scan confirms an intrarenal tumor. All patients receive 6 weeks of preoperative chemotherapy with vincristine, actinomycin-D and adriamycin. Vincristine is administered weekly while actinomycin-D is given on week 1, 3 and 5. Adriamycin is given on week 1 and 5 only. Patients are then scheduled for surgery on the 7^{th} or 8^{th} week of treatment. Staging of the disease is done intra-operatively and using imaging to detect lung or liver metastasis. Staging guides the decision on post-operative treatment. Post-operatively patients with stage I disease are given 4 weeks of vincristine and actinomycin-D. Children with stage II and III disease are given 16 weeks of vincristine and actinomycin-D. Children with stage III disease are referred for radiotherapy as well. Children with stage IV disease and those with anaplastic histology despite the stage are given vincristine, actinomycin-D and adriamycin for 16 weeks. Stage V disease patients receive the same preoperative chemotherapy outlined above and then the decision on further treatment depends on pre-operative imaging and the findings at surgery.

Study Design

This was a retrospective medical records study. The study inclusion criteria were all children presenting with a Wilms' tumor at MTRH between 1^{st} January 2010 and 31^{st} December 2012 aged between 0-16 years at diagnosis. It is important to state that we did not select patients for our analysis, but included all patients who received a diagnosis of Wilms' tumor.

The names and inpatient numbers of patients diagnosed with Wilms' tumor were extracted from the pediatric oncology database. Files were obtained from the medical records department. Socio-demographic and clinical characteristics was extracted from patients' medical records using a data collection form.

The socio-demographic characteristics included age at diagnosis, gender, ethnicity, patient's residence, and enrollment in NHIF. The patient's residence was used to compute the distance from MTRH, which was subsequently categorized into distance ≤100 kilometers and >100 kilometers.

The clinical characteristics were date of diagnosis, staging of disease, time to events and treatment outcomes. The disease was staged using imaging to detect any lung or liver metastasis, as well as the information derived from the intra-operative findings. For further analysis on outcomes we grouped the non-metastatic stages I to III as "low stage," and stage IV and V as "high stage." Treatment outcomes were classified as abandonment of treatment, death, progressive or relapsed disease and event-free survival. Abandonment of treatment was defined as either failing to begin or to continue planned treatment during 4 or more sequential weeks.(11)

Data Analysis

Data analysis and management was done using SPSS version 20. Frequency distributions, means and medians were calculated. The relationship between treatment outcomes and socio-demographic or clinical characteristics was evaluated by the chi-squared and Fisher's Exact test. The probability of event-free survival was estimated by the method of Kaplan-Meier: estimates were compared with log-rank test. Event-free survival was measured from date of Wilms' tumor diagnosis until the first treatment failure or the date of last follow-up. Treatment failures included abandonment of treatment, death, and progressive or relapsed disease.

RESULTS

A total of 39 Wilms' tumor patients presented to the hospital during the study period. Females comprised 52% of patients. Table 1 presents socio-demographic and clinical characteristics.Almost all patients (97%) were referred to MTRH from other health facilities. The majority (91%) were referred from secondary level public health facilities, while the rest were referred by a private clinic (3%), private hospital (3%), and tertiary

level hospital (3%). Before patients presented to MTRH only 16% had been given a possible diagnosis of Wilms' tumor, while none had received any treatment specific for Wilms' tumor. The majority of patients presented late. There was no patient with stage I disease. Children were diagnosed with: stage II (7%), stage III (43%), stage IV (40%), and stage V (10%) disease.Of all 39 patients, 54% lived more than 100 km from MTRH. At time of diagnosis 39% of patients had NHIF. Of those who did not have NHIF at diagnosis, most (83%) registered while undergoing treatment at MTRH bringing the total enrollment level to 90%.

Table 1. Patients' socio-demographic and clinical characteristics (n=39).

Characteristics	**N (%)**
Age at diagnosis in months	
mean ± SD	51 (± 29)
median (range)	53 (5-147)
Gender	
Male	19 (49%)
Female	20 (51%))
Tribe (n=37)	
Luhya	16 (43%)
Kalenjin	10 (27%)
Luo	6 (16%)
Kikuyu	3 (8%)
Teso	(3%)
Kisii	1 (3%)
Distance to MTRH	
≤ 100 km	18 (46%)
>100 km	21 (54%)
Duration of symptoms before first hospital admission at MTRH (n=36)	
1-3 months	24 (67%)
>3 months	12 (33%)
Stage of disease at diagnosis (n=30)	
Stage I	0 (0%)
Stage II	2 (7%)
Stage III	13 (43%)
Stage IV	12 (40%)
Stage V	3 (10%)
Health-insurance (NHIF) status at diagnosis	
NHIF	16 (41%)
No NHIF	23 (59%)

Table 2 shows that the most common cause of treatment failure was abandonment of treatment (31%).All patients abandoned treatment within the first 6 months after diagnosis. The second most common cause of treatment failure was death (23%).All deaths occurred within 4 months of diagnosis, with 78% of these children dying within the first 2 months. The least common treatment failure was progressive or relapsed

disease (5%). Figure 1 presents the event-free survival estimate of all children with Wilms' tumor.

Table 2. Treatment outcomes in children with Wilms' tumor, and the influence of stage of disease, distance to hospital, and health-insurance status on treatment outcomes (n=39).

Overall Patient Population			
Abandonment of treatment	12 (31%)		
Death	9 (23%)		
Progressive or relapsed disease	2 (5%)		
Event-free survival	16 (41%)		
Stage of Disease (n=30)	**Low***	**High****	**P**
Abandonment of treatment	5 (33%)	3 (20%)	0.014
Death	0 (0%)	6 (40%)	
Progressive or relapsed disease	0 (0%)	1 (7%)	
Event-free survival	10 (67%)	5 (33%)	
Distance to Hospital	**≤ 100 km**	**> 100 km**	**P**
Abandonment of treatment	4 (22%)	8 (38%)	0.074
Death	2 (11%)	7 (33%)	
Progressive or relapsed disease	2 (11%)	0 (0%)	
Event-free survival	10 (56%)	6 (29%)	
Health-Insurance Status	**NHIF*****	**No NHIF**	**P**
Abandonment of treatment	4 (25%)	8 (35%)	0.640
Death	4 (25%)	5 (22%)	
Progressive or relapsed disease	0 (0%)	2 (9%)	
Event-free survival	8 (50%)	8 (35%)	

* **Low**, stage I-III disease ** **High**, stage IV-V disease *** **NHIF**, National Hospital Insurance Fund

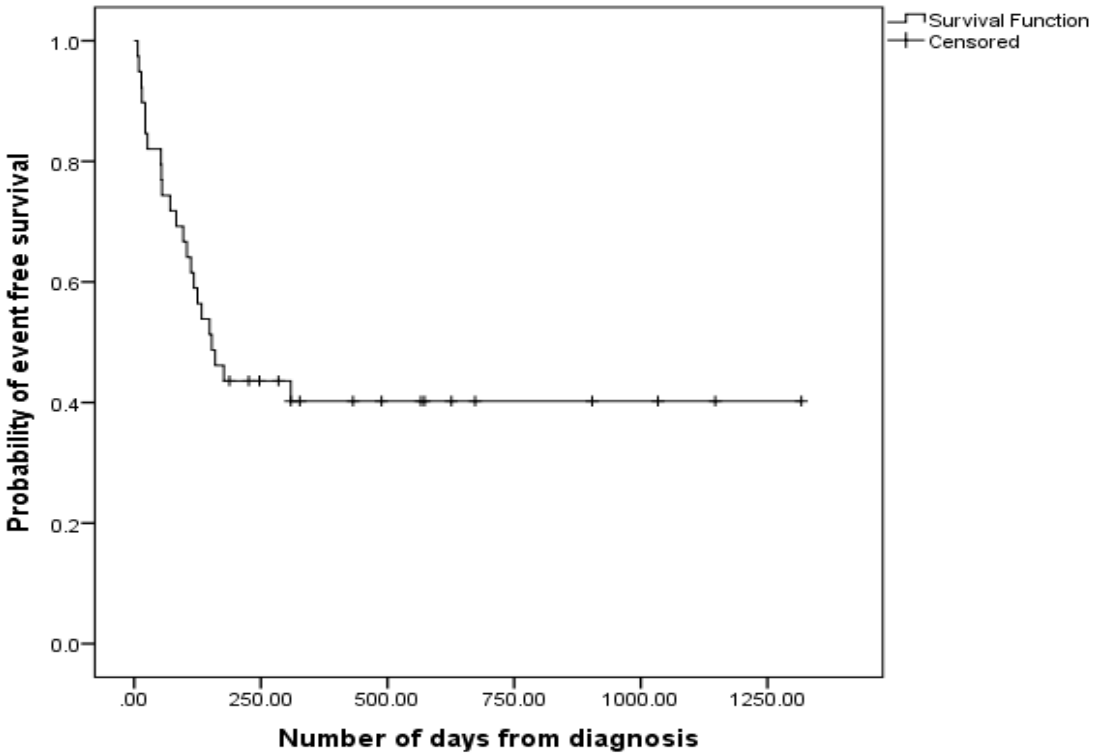

Figure 1. Kaplan-Meier estimates of event-free survival in children with Wilms' tumor (n=39). Events included abandonment of treatment, death, and progressive or relapsed disease

Of 30 patients with documented stage of disease, 50% had low (I-III) stage disease and 50% high (IV-V) stage disease. The most likely treatment outcome in patients with low stage disease was event-free survival (67%), whereas in patients with high stage disease it was death (40%).No death and progressive or relapsed disease occurred among patients with low stage disease.Table 2 illustrates that differences in treatment outcomes between children with low or high stage disease were significant (P=0.014).Figure 2 shows that event-free survival estimates differed significantly between patients with stage II, III, IV or V disease (P<0.001).

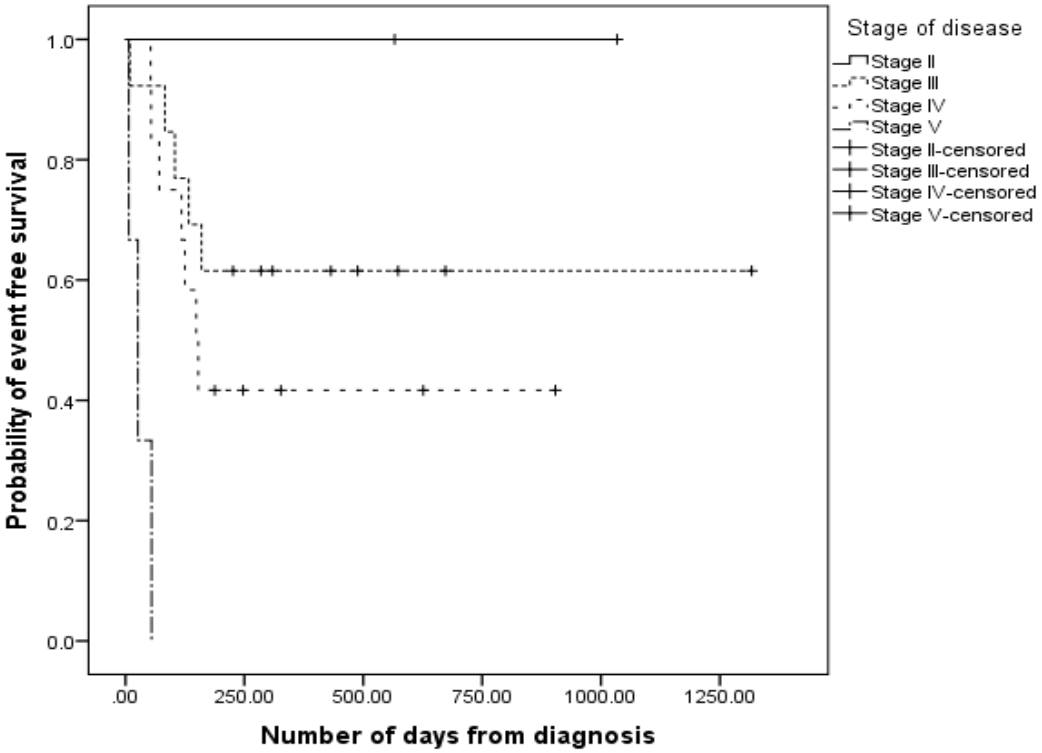

Figure 2. Kaplan-Meier estimates of event-free survival in children with Wilms' tumor per stage of disease at diagnosis (P<0.001). Events included abandonment of treatment, death, and progressive or relapsed disease

The other patients' socio-demographic and clinical characteristics (age at diagnosis, gender, duration of symptoms, distance to hospital, and health-insurance status) did not have a statistical significant influence on treatment outcomes and event-free survival estimates. Figure 3 and 4 illustrate that living at shorter distance from MTRH and having health-insurance at diagnosis led to better chances of survival, but this did not reach statistical significance (P=0.063 and P=0.358 respectively).

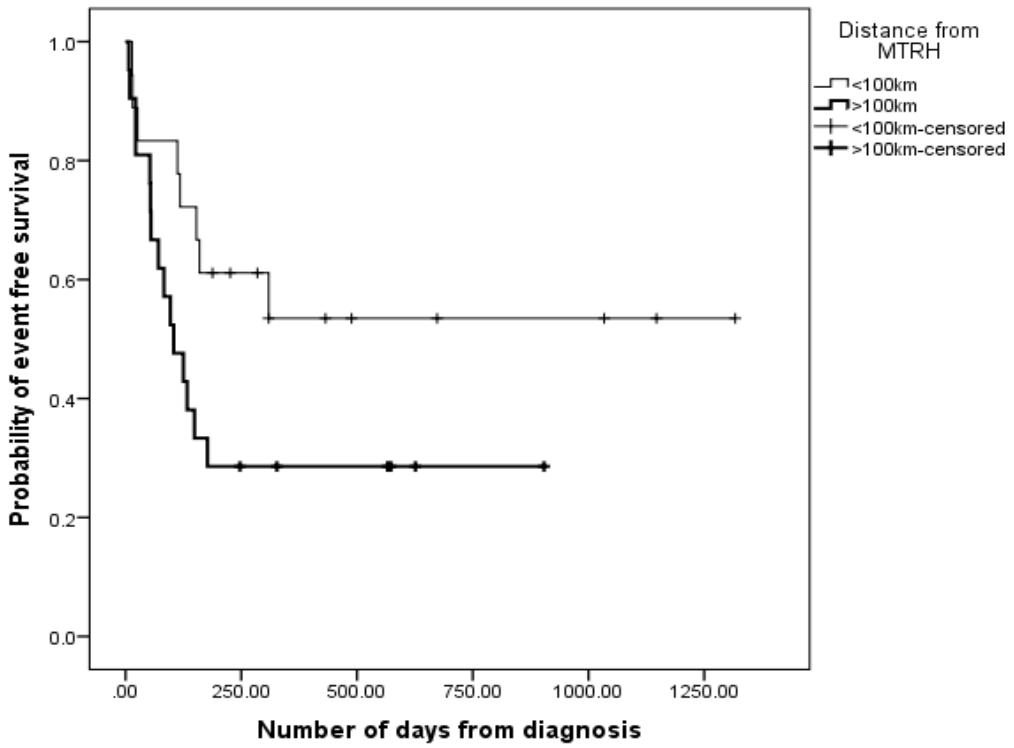

Figure 3. Kaplan-Meier estimates of event-free survival in children with Wilms' tumor per distance to hospital (P=0.063) Events included abandonment of treatment, death and progressive or relapsed disease

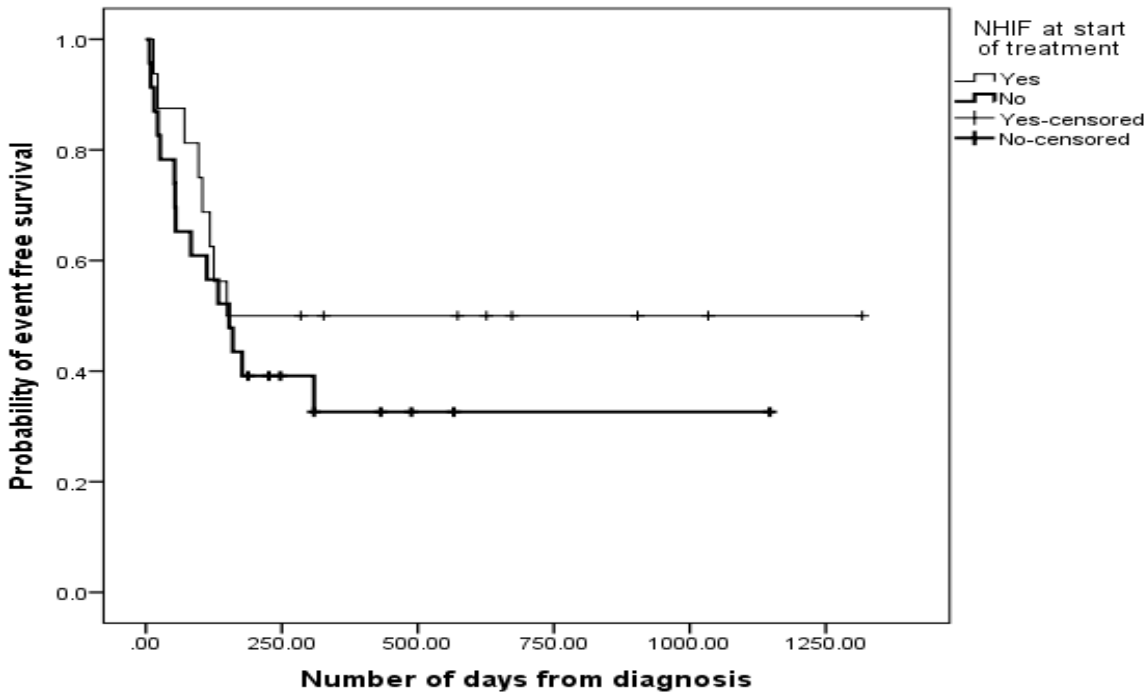

Figure 4. Kaplan-Meier estimates of event-free survival in children with Wilms' tumor per health-insurance status at diagnosis (P=0.358). Events included abandonment of treatment, death, and progressive or relapsed disease

DISCUSSION

This study demonstrated a survival rate of 41% among the patients diagnosed with Wilms' tumor at MTRH in the years 2010 to 2012. This is a great improvement from the survival of 29% that was documented for the patients who were treated in the institution between the years 2000 and 2007.(12) This improvement may be attributed to several factors. The hospital adopted the SIOP approach to the management of Wilms' tumor during the time frame of this current study. In the previous study some patients never received any preoperative chemotherapy and mortality was quite high. In 2009 the hospital came up with a protocol manual that was used to manage all patients with cancer. Use of protocols and a multidisciplinary team have demonstrated to lead to better outcomes. We now have competent pediatric surgeons, psychological counsellors, social workers and pharmacists involved in the care of patients with Wilms' tumor. A team of dedicated pediatric oncology nurses takes care of the children, unlike in the past when nurses were moved from the department every few months. This has increased nurses' knowledge and experience which resulted in better patient care. Supportive care has also improved over time using a protocol for management of febrile neutropenia and better availability of antibiotics. Nutritional care has ameliorated significantly. Previously cultural beliefs and associations with death prevented both the medical team and the families to use nasogastric feeding. Now most children do get nasogastric tube feeding which allows feeding even when children have low appetite or suffer mucositis. All patients were also actively encouraged to register with NHIF and given assistance whenever possible. All these interventions have been achieved through collaboration with two partners in high-income countries: the Indiana University School of Medicine from the USA and the VU University Medical Center from the Netherlands. The twinning has led to the transfer of knowledge amongst doctors, nurses and other support staff. This is achieved through exchange visits, teleconferences that discuss patient care and training workshops that are held in Eldoret every year.

High-income countries have reported a very high survival rate among children with Wilms' tumor. In the United Kingdom an overall survival rate of 88% was documented on a 10 year follow-up.(13) Middle-income countries also have good survival rates with China reporting a survival rate of 81%.(14) However the survival rates are still very low in low-income countries, especially in Africa. A two year survival rate of 25% has been reported from an eight center Wilms' tumor treatment

collaborative effort in Africa.(15) In Malawi the survival is 46%.(16) These low survival rates have been attributed to several factors including high treatment abandonment and treatment-related mortality.(17)

The rate of treatment abandonment was 31%. This is a decrease from the 54% abandonment rate that we reported before in the same hospital for the period 2007-2009, although the latter study looked at all types of cancer.(18) This figure is also lower than the 42% reported previously among Wilms' tumor patients in the same institution.(12) In a study that looked at several hospitals in Kenya a lost to follow-up rate of 50% was reported among Wilms' tumor patients though this included both those who abandoned therapy, as well as those who were lost to follow-up after finishing treatment.(19) In Africa, Wilms' tumor treatment abandonment rates vary between 14-48%.(15) Abandonment in this set-up is attributed to lack of parental education on Wilms' tumor by medical staff, parents' misunderstanding of treatment protocol and families' financial difficulties.(20) Abandonment of therapy contributes to a large extent to poor outcomes of pediatric oncology in low-income countries. In this study abandonment was the only adverse outcome among those patients with stage II and III disease. If this phenomenon is addressed adequately it could improve the survival in this group close to what is reported from high-income countries.

The majority of patients of our study presented with late stage disease. Those who had stage II disease had good outcomes as opposed to those with later stages of disease. In a multicenter study on Wilms' tumor involving French speaking countries in Africa was reported that stage III and IV disease included 41% of all cases.(17) In South-Africa stage III and IV disease made up 49% of the cases.(21) In both latter studies patients with stage V disease had been excluded for analysis. This indicates that late presentation is still a major issue in low-income settings. It could possibly be explained by circumstances that lead to both patient and health-care system delays. The patient delays are usually due to health beliefs, poor reputation of public hospitals, preference for alternative medicine, and financial difficulties coupled with lack of health-insurance. The health-care system delays are due to unavailability of qualified personnel or equipment required to make the right diagnosis.(22,23)

Stage of disease has been documented as one of the most important prognostic factors. However, there are still huge differences when we compare outcomes in high versus low-income countries. In the United

Kingdom an overall survival of 81% for stage IV disease has been reported.(13). In Africa among the French speaking collaborative group children with stage IV disease had an overall survival of 49%, while in South-Africa their survival was 57%.(15,21) Disparities in survival between high and low-income countries are worse in the more advanced disease stages, yet most patients from low-income countries present with advanced disease. To improve outcomes we therefore should not just concentrate on improving the standards of care, but also on diagnosing patients with early stage disease. Increasing awareness among health-care workers about childhood cancer is paramount. Having ultrasound machines as well as trained personnel in most primary care centers could lead to increased detection rates. This strategy could have the potential of increasing survival with less strain on the health-care system.

Patients living more than 100 kilometers from MTRH had lower chances of survival compared to those who lived nearer to the hospital, although this did not reach statistical significance. The most likely treatment outcome in patients within 100 km distance to MTRH was event-free survival, whereas in patients living further from MTRH it was abandonment of treatment.Distance and transport costs have been demonstrated to increase chances of abandonment and thereby decrease survival in pediatric oncology.(24,25) In a previous study among families of children with cancer who abandoned treatment at MTRH was found that long distance to hospital led to higher costs of transportation and affected the ability to turn up for appointments.(18) Most Kenyan families use public transport to reach MTRH. Kenya's public transport however is not well organized. The number and quality of roads are limited. There are no fixed routes, timetables or fares.(18) These infrastructural obstacles may ultimately affect the survival of children with Wilms' tumor.

Although only 39% of families had health-insurance before coming to MTRH, this number is higher than the national figures of 10%.(26). Previous studies in the Kenyan setting showed that having NHIF at diagnosis significantly decreased abandonment and improved childhood cancer survival.(18,20) This taught our team that it is important to enroll patients in NHIF. In the pediatric oncology ward at MTRH the doctors and nurses therefore now continually inform families about the need for NHIF. Particularly for children with potential good prognosis, like Wilms' tumor, medical staff makes sure that families get NHIF. Support staff helps families to collate all documents required for this purpose and directs them on which office to go to. Most families in our study

subsequently enrolled in NHIF during hospitalization. This illustrates that if families are given the right information and are facilitated to obtain health-insurance many of them are willing to do so. The government should have mass media education campaigns on the benefits and procedure of registering with NHIF.

The main limitations in this study were the small sample size and that some data was missing since it was a retrospective chart review.

In conclusion, the survival of Wilms' tumor patients at MTRH has improved between the years 2010 to 2012 as compared to 2000-2007. The main reason of treatment failure was abandonment of treatment. Stage of disease at diagnosis significantly affected treatment outcomes and event-free survival estimates. Age at diagnosis, gender, duration of symptoms, distance to hospital and having health-insurance at diagnosis did not predict survival.

Based on the findings of our study, we acknowledge that abandonment of treatment needs to be addressed. Giving proper parental education and providing financial support would be useful strategies. To help reduce the number of children presenting with late stage disease and improve the access to conventional health-care facilities we recommend that government should install mandatory universal health-insurance coverage. Health-care workers should be trained on the clinical features of Wilms' tumor. This should be done by incorporating training on childhood cancers into the curricula of medical training institutions, as well as through continuous professional development for those already graduated. To reduce transportation difficulties for families living far from hospital, setting up satellite clinics and a family's guesthouse near the hospital could be beneficial. Ultimately all these interventions could improve survival of children with Wilms' tumor.

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CHAPTER 11

HOSPITAL DETENTION PRACTICES: STATEMENT OF A GLOBAL TASKFORCE[†††]

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Hospital detention practices can be defined as refusal to release living patients after medical discharge is clinically indicated, or refusal to release bodies of deceased patients, when families are unable to pay their hospital bills.[1-3] Each additional day for which patients are detained adds to their bills, increasingly hindering families' ability to obtain patients' release.[2] Patients are sometimes detained in hospitals, or bodies detained in mortuaries, for months.[1-3] Occasionally, patients are completely left behind when families are unable to pay.[1-3] Unclaimed patients' bodies may be disposed of in mass graves.[1,3]

The problem's magnitude is unknown, but is probably more widespread than is documented.[4] Hospital detention has been reported by human rights organisations, clinicians, journalists and laypeople in Africa, Asia, Latin America and eastern Europe.[1-4] The problem affects children and adults with acute disorders (eg, people involved in road accidents and women with birth complications) and chronic diseases (eg, cancer or HIV/AIDS).[1,3] Reports do not have consistent terminology to enable comparisons of studies worldwide or to effectively unite forces.[1-4]

We have formed the International Society of Paediatric Oncology and Paediatric Oncology in Developing Countries (SIOP PODC) Global Taskforce on Hospital Detention Practices, with the following objectives: to augment critical awareness; to introduce consistent terminology; to help to map global scope reliably; to elucidate adverse consequences; to address root causes; and to identify and support implementation of effective solutions to end hospital detention practices.

The Taskforce endorses the following core statements related to each objective.Patients' detention violates international human rights, including the right to not be imprisoned as a debtor and to have access to medical care.[1,5] Recommended terminology includes "hospital detention practices" and "detained patients." The term "detention" minimises confusion with positive health-care retention in medical literature.[1] The term "practices" more accurately describes reality than does "policies." Although hospital detention is often not the official policy publicly defended by governments, it may be a widespread unofficial practice. To map the global scope, the Taskforce calls on professionals and advocates to report hospital detention in scientific journals, media and public venues. Recognition of adverse consequences is crucial. Fear of detention might prevent or delay conventional medical help-seeking, and encourages abandonment of potentially curative treatment after patients' release. Progressive or relapsed disease and unnecessary death often

result. Detention aggravates hospital overcrowding, increases infection risk and denies schooling to children.[1,2] Hospital detention is often the result of mismanagement, corruption, dysfunctional health-system structures, inadequate health insurance coverage, and unfair waiver procedures warranting attention.[1,2] Advocacy by stakeholders is urgently needed (panel).

Our Taskforce endorses this position statement in the conviction that detention of patients is unethical and inhumane, and must end.

We declare no competing interests.

Panel. Recommendations to end hospital detention practices through collaboration of five key groups of stakeholders

International financial institutions, health-organisations and donor countries:

- Demand that governments end hospital detention practices
- Apply diplomatic pressure
- Use aid to address healthsystem governance, implement healthinsurance coverage, and end hospital detention

United Nations:

- Establish a global monitoring framework to investigate, and report on hospital detention practices
- Counsel governments about how these abuses should be addressed
- Coordinate funding for projects to eliminate hospital detention
- Consider an International Convention on Protection of Patients' Rights to specifically address hospital detention

National governments:

- Free all detained patients
- End hospital detention practices
- Install legislation to make the practice actionable by law
- Implement healthinsurance coverage

National and local civil-society organisations:

- Foster awareness
- Provide legal support to detained patients
- Pressure governments to end hospital detention practices

International medical organisations and scientific journals:

- Raise awareness
- Encourage research into evidence-based strategies to address hospital detention practices
- Promote partnerships to take positive, concerted action

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CHAPTER 12

SUMMARY

Chapter 1 describes the challenges faced in treatment of childhood cancer in low-income countries. Globally there are about 200,000 new cases of childhood cancer annually of which 80% occur in low and middle-income countries. Eighty per cent of deaths due to childhood cancer occur in low and middle-income countries. The survival is more than 75% in high-income countries while it is less than 35% in low and middle-income countries. There are a variety of reasons that explain this huge difference in survival. These include inadequate financial and human resource, and treatment related mortality. However, the most important reason for this difference in survival is abandonment of treatment, which is almost never seen in high-income countries.

The aims of this study are:

i) To investigate the epidemiology of childhood cancer at MTRH

ii) To explore treatment outcomes and survival of childhood cancer at MTRH

iii) To assess the magnitude and the factors which contribute to childhood cancer treatment abandonment in Kenya.

iv) To investigate the barriers to accessing health care for childhood cancers in Kenya

Chapter 2 describes the epidemiology of diagnosed childhood cancer in Western Kenya. This was done through a retrospective medical records study performed at the Moi Teaching and Referral Hospital (MTRH) located in Eldoret, Kenya. All children aged less than 19 years who presented to the hospital between January 2006 and January 2010 with a newly diagnosed malignancy were included. Three databases were used to identity these children and we found a total of 436 children with 59% being male. Non-Hodgkin lymphoma was the most common type of cancer (34%) followed by acute lymphoblastic leukemia(15%), Hodgkin lymphoma(8%), and nephroblastoma (8%). Majority of the children were between 6-10 years (29%). We found that the distribution of childhood cancers in Western Kenya is the same as what has been described in other Sub-Saharan Africa countries, but differs markedly from those in high-income countries.

Chapter 3 focuses on the problem of treatment abandonment in the Kenyan set-up. Between January 2007 and January 2009 treatment abandonment was the leading cause of childhood cancer treatment failure at MTRH. We had found an abandonment rate of 54% among the 180 patients diagnosed during this period.The aim of this study was to assess thereasons for treatment abandonment and the clinical condition of these children. This was a descriptive study using semi-structured questionnaires.Home visits were conducted to interview the families of children with cancer, diagnosed between January 2007 and January 2009, who had abandoned treatment at MTRH. Due to lack of contact information, only 53 families could be traced. In total, 46 families (87%) agreed to be interviewed. The most common reasons for abandonment were financial difficulties(46%), inadequate access to health insurance (27%) and transportation difficulties(23%). Most patients (72%) abandoned treatment after the first 3 months had been completed. Twenty per cent of the children who abandoned treatment were still alive at the time of conducting the interviews.

In **Chapter 4** we looked at two unique factors that might be contributing to the high abandonment rate in this set up. These were hospital retention policies and access to health-insurance. This study explores whether childhood cancer treatment outcomes in Kenya are influenced by health-insurance status and hospital retention policies. We reviewed the medical records of children diagnosed with malignancy in the years 2007 to 2009 and used a case report to illustrate the contribution of these two factors to abandonment. Among the 222 children diagnosed during this time frame, 180 had documented outcomes. The majority (54%) abandoned treatment, 19% had event-free survival with the rest having progressive/relapsed disease or death. Health-insurance status at diagnosis was recorded in 148 children: 23% had health-insurance, and 77% had not. For those with health-insurance compared to those without, the relative risk for treatment abandonment relative to event-free survival was significantly smaller(relative-risk ratio=0.31, 95% CI 0.12-0.81, P=0.016). The case reported was on a child diagnosed with acute lymphoblastic leukemia whose family did not have health-insurance at diagnosis and the boy was retained in the hospital as the family could not pay the hospital bill.

In **Chapter five** we looked at the effect of parents' social network and hospital retention policies on parents' decisions to abandon cancer treatment of their child. We did this by conducting home visits to families that had abandoned childhood cancer treatment at MTRH in the years

2007-2009. We managed to interview 46 of those families. Their social network comprised the grandparents, relatives, friends, villagers and church members. Majority (74%) of the families were advised by those in their social network to seek alternative treatment, while 54% were advised to stop the hospital treatment. Parents also reported that they were influenced by discussions with other parents who had children with cancer as they told them the life of the child was in God's hands (87%), the trauma to the child and family of forced hospital stays (84%), the importance of completing treatment (81%), the financial burden of treatment (77%), and the incurability of cancer(74%).Seventy-eight per cent of the families had no health-insurance and 53% of them had their children detained in the hospital due to non-payment of hospital bills. The families had a lot of negative feelings about the detention: desperation (95%), powerlessness (95%), and sadness (84%). The majority of parents (87%) felt that hospital retention of children must stop.

Chapter 6 describes the experiences parents go through as their children undergo cancer treatment at MTRH. This was done by conducting face to face interviews with parents whose children with cancer came for treatment between November 2012 and April 2013.Semi-structured questionnaires were used. We assessed the socio-economic, psychological and treatment related experiences. We had a response rate of 65% and were able to interview 75 parents. Cancer treatment resulted in financial difficulties (89%).Most families (63%) had no regular source of income while 66% reported that the income reduced while the child was undergoing treatment.Most of the families felt that they needed more information about cancer(88%) and more contact with doctors (83%). At diagnosis, cancer was perceived as curable (63%). Yet, parents were told by health-care providers that most children with cancer die (49%).Most parents reported using complementary alternative medicine(95%) although they found it difficult to discuss the same with the doctors(88%). They had varied reasons for using complementary medicine: hope for cure(53%), hope for improvement of child's condition(47%),and recommendation by others(37%). Community members advised to use complementary alternative treatment (61%), believed that the child was bewitched (57%), and isolated families because their child had cancer.Parents shared experiences with other parents at the ward (97%) and would otherwise not understand cancer and its treatment (87%).

In **Chapter 7** we evaluated the health-care providers' perspectives on childhood cancer. Using a self-administered questionnaire which was filled out by 104 staff who work in the Department of Pediatrics at MTRH. Seventy-six percent of the health-care providers believed that cancer is curable. More doctors than other health-care workers believed that cancer is curable (P=0.037). Majority of health-care providers (92%) believe most children with cancer will not be able to finish their treatment due to financial difficulties. They believe that prosperous highly-educated parents adhere better with treatment (88%) and that doctors adhere better with treatment for prosperous highly-educated parents (79%). According to 74% of health-care providers, quality of care is improved towards prosperous highly-educated parents (74%). Most health-care providers report to give more explanation (71%), work with greater accuracy (70%) to prosperous more educated families. Only 34% of health-care providers reported they feel more empathy towards patients from prosperous families. Reasons for non-adherence with the protocol according to health-care providers are: family refuses drugs (85%), inadequate supply of drugs at pharmacy (79%), child looks ill (75%), and financial difficulties of parents (69%). Health-care providers' health beliefs and attitudes differ between families with high versus low socio-economic backgrounds.

Chapter 8 is a review of the problem of corruption and how it affects cancer care in Africa. We searched Pubmed and Google for relevant articles published between January 1990 and February 2015. We included articles with the terms "corruption" and "low-income countries" or "Africa". Corruption is the use of entrusted power for private gain.The corruption perception index, a scale ranking countries from 0 (very corrupt) to 100 (very clean), is currently lower than 50in 91% of the African counties.The health-care system is vulnerable to corruption since there are many players involved at different levels and there is an imbalance of medical knowledge among the different players.At the government level, misallocation of resources, diversion of resources, nepotism and poor monitoring systems are major components of corruption. This is replicated at the hospital level, as well as poor maintenance of equipment and diversion of supplies to private facilities.At the health-care provider level there are many doctors involved in dual physician practices and absenteeism. Some health-care providers also ask for informal payments before they provide services to staff and some are involved in diversion of supplies to their private clinics.Corruption therefore leads to delays in cancer patients seeking care as they avoid the public health facilities. It also leads to

abandonment of treatment as the patients incur high costs due to unavailability of drugs and the demands for bribes. Thereare delays in making and implementing decisions on patient care due to absence of the senior doctors. This leads to prolonged hospital stays among other effects. We have suggested several recommendations to international financial institutions, health organizations, donors, the United Nations, governments in high-income countries, African governments, and to the hospitals and health-care workers which we hope can reduce the magnitude of the problem.

In **Chapter 9** we explored the factors that influence the time to diagnosis and treatment among pediatric oncology patients in Kenya. We conducted a study among parents of childhood cancer patients diagnosed between August 2013 and July 2014 at the MTRH in Eldoret, Kenya. Patient, physician, diagnosis, treatment, health-care system, and total delay were explored using a questionnaire. Demographic and medical data were collected from the patients' medical records. Parents of 99 childhood cancer patients were interviewed (response rate: 80%). Median total delay was 102 (9–1021) days. Patient delay (4 days) was significantly shorter than health-care system delay (median 87 days;P <0.001). Diagnosis delay (median 94 days) was significantly longer than treatment delay (median 6 days; P <0.001). days. Lack of health insurance at diagnosis and use of alternative medicine before attending conventional health services were associated with a significantly longer patient delay (P =0.041 and P =0.017, respectively). The type of cancer had a significant effect on treatment delay (P =0.020). The type of health facility attended affected only patient delay (P=0.030). Gender, age at diagnosis, stage of disease, parents' education level or income, and distance from hospital did not have a significant effect on the length of any type of delay.

In **Chapter 10** we report on the outcomes of Wilms' tumor treatment in Western Kenya.This was a retrospective medical records review of all children diagnosed with Wilms' tumor between 2010 and 2012. Data on treatment outcomes and various socio-demographic and clinical characteristics was collected. Of all 39 Wilms' tumor patients, 41% had event-free survival, 31% abandoned treatment, 23% died, 5% had progressive or relapsed disease. Most patients presented at advanced stages: stage I (0%), stage II (7%), stage III (43%), stage IV (40%), stage V (10%). The most likely treatment outcome in patients with low (I-III) stage disease was event-free survival (67%), whereas in high (IV-V) stage disease it was death (40%). Stage of disease significantly

impacted treatment outcomes (P=0.014) and event-free survival estimates (P<0.001). Age at diagnosis, gender, duration of symptoms, distance to hospital, and health-insurance status did not statistically significantly influence treatment outcomes and event-free survival estimates. Survival of Wilms' tumor patients in Kenya is lower compared to high-income countries. Treatment abandonment is the most common cause of treatment failure. Stage of disease at diagnosis statistically significantly affects treatment outcomes and survival.

Chapter 11 is a position statement from the International Society of Paediatric Oncology Global Taskforce on hospital detention practices. It recommends and defines the terms "hospital detention practices" and "detained patients." It calls on professionals and advocates to report hospital detention in scientific journals, media and public venues. Recognition of adverse consequences is crucial. Progressive or relapsed disease and unnecessary death often result. Hospital detention is often the result of mismanagement, corruption, dysfunctional health-care system structures, inadequate health-insurance coverage, and unfair waiver procedures, warranting attention. Advocacy by stakeholders, such as international financial institutions, health organisations, donor countries, United Nations, national governments, civil society organisations, and scientific journals, is urgently needed.

CHAPTER 13

GENERAL DISCUSSION

Between the years 2006 to 2009 MTRH received an average of 109 patients every year. This is a far lower than expected number given the catchment area that the hospital serves.Internationally childhood cancer has an incidence rate of about 120-140 per million children less than 15 years anually.MTRH is the only center that provides care for diverse types of childhhod cancers in the Western region of Kenya.The catchment area of MTRH has about 6 million children under the age of 15 years which would mean that we expect at least 700 patients to be seen at MTRH every year.

There are various reasons why the number of children diagnosed with cancer would be lower than expected. Low parental education and awareness on health issues leads to poor health seking behaviours and hence they are unlikely to go to hospital whenever the child is ill. Parents may also not present to the cancer treatment center if they are told that their child has cancer in a lower level facility as parents may believe it is incurable. Other parents may opt for alternative medicine.Others may have financial difficulties and are thus unable to come to the hospital for proper diagnosis and treatment. The health-care providers may also have inadequacies in diagnosing childhood cancer and the hospital may lack proper diagnostic equipment.Sometimes the health care workers do not believe that cancer is curable and hence may not refer the patients appropriately. Finally even after diagnosis there could be loopholes interms of having the patients appropriately registered. If hospitals have no data entry clerks or lack the required equipment, this compromises the registration system.

The distribution of malignancies at MTRH is the same as that reported from other Sub-Saharan Africancountries. Non-Hodgkin lymphoma was the commonest followed by acute lymphoblastic leukemia then nephroblastoma. Non-Hodgkin lymphoma, especially the Burkitt type is more comon in Sub-Saharan Africa due to the association with Malaria and Epstein Barr virus in its pathogenesis. The number of cases of acute lymphoblastic leukemia are very low when compared to the high income countries(2 per million vs 41 per million). The symptoms of acute leukemia are very similar to those of malaria and other infectious conditions that are quite common in this set-up. The patients then get treated for these other conditions and die before a correct diagnosis is

made.Brain tumors were very few in our population when compared to the statistics from high-income countries. This could be due to the limited imaging facilities in this set up which are required for diagnosis.

Data collection was a difficult task during this time period as there was no comprehensive register for the childhood cancers and we had to rely on information from these different sources which may mean also that some children were missed out.Proper record keeping is of utmost importance to be able to know the magnitude of the problem as well as plan for the care of the patients and be able to lobby the government and other organizations to provide resources to care for these patients.

Treatment abandonment at MTRH during the period 2006-2009 was 54%. This is quite a high figure though similar to what has been reported in other low income countries. The reasons given by the families for abandoning treatment were diverse. The most commonly reported was financial difficulties followed by inability to access NHIF. Other reasons were transportation difficulties and the fact that some health-care providers informed the families that nothing could be done about the childs condition, the child'condition did not improve, dissatisfaction with the health-care providers, belief that cancer is uncurable, as well as the child's wish to abandon treatment.

Financial difficulties and transport challenges have been reported in many studies as contributing to abandonment. In this study we found lack of acces to the NHIF as a unique phenomenon. NHIF enrollment is cheap but many families feel that the procedures for registration are complicated. The medical personnel also do not give adequate information to families regarding NHIF.

Most of the families abandoned treatment more than three months after start of treatment as opposed to what has been reported in most other studies where abandonment occurs within a few weeks after diagnosis. Ar MTRH, the hospital usually provides care for patients upfront. Families then need to pay most of the blll at discharge. The families that are unable to pay are detained in the ward until they can pay or until the bills are waived. This could explain the long duration before abandonment.

Many families felt that they did not abandon treatment despite that the medical records showing they had. Thiscould mean that the families did not understand the treatment schedule. However this may also mean that this is a subject that is a bit sensitive and families may feel like they let down the child if they affirm that they abandoned treatment.

Two other interesting phenomenons relating toabandonment came up in this study. The first is the influence of the social network. The socoal network refers to individuals or groups of individuals that offers a person or family social support, in this case the family whose child has cancer. This network in the Kenyan context includes grandparents, relatives, fellow villagers and church members. It would be expected that having such a wide and diverse group of people whose opinions are taken seriously whenever making important decisions in the African context would be beneficial.However we found that this network did not always encourage families to seek conventional health care but advised them to go for alternative medicine. They also advanced misconceptions and beliefs about cancer. About half of the parents we interviewed were strongly advised to stop treatment at MTRH. It is also important to note that this social network was quite helful when it came to raising funds for the children to undergo treatment. It may also in a way explain why families listen to them when making decisions regarding their child's treatment. If they went against the opinion of the community members their financial support would be withdrawn yet most of the families are very poor.

The other unique issue relating to treatment abandonment that we found out from this study are the hospital detention practices.Hospital detention practices are defined as the refusal to release living patients after medical discahrage is clinically indicated or refusal to release bodies of deceased patients when families are unable to pay medical bills.

Most of the families in Kenya do not have medical insurance. They are supposed to pay for their medical expenses from their own pockets. Almost half of the citizens live below the poverty line. This therefore means after getting medical care in hospitals they are unable to pay for the bills after discharge. If they are unable to cllear the bills the children are detained in the hospital until they can do so or until the bills are waived. Waiving the bill usually requiresa waiving procedure whereby the hospital writes of all or part of the bill. However, many families are unaware of the waiving procedire when they come to the hospital. The rules on waiving are also not very clear making the system prone to abuse and may therefore not benefit the most needy.

Once children are detained the parents experience a lot of negative feelings. The separation from the child is a traumatic experience for most parents.The parents also feel desperate, sad, powerless, depressed, imprisoned among others feelings.The hospital bill for the child increases

every day that they are detained and this worsens the situation. Families that had their chidren detained in the hospital were less likely to come for subsequent appointments due to these feelings inscreasing the abandonment rate.Knowledge of hospital detention practices among parents also decreases their likelihood to come to the hospital for care.This may contribute to the low number of children registered with cancer in Kenya. In addition, it contributes to delay in diagnosis and treatment of the children.

The problem of hospital detention is not yet fully described globally. It is a human rights issue which needs to be adressed at various levels.The international medical organizations and journals need to increase publicity about this issue and encourage evidence based research that can resolve the issue. The international financial institutions and donor countries should pressurise countries to end the practice and help improve governance systems within health-care. The United Nations should help form an investigative and monitoring mechanism to report the countries that engage in the practice as well as advising governments on how they can end the practice. The governemnts of each individual country should end hospital detention practices and enact laws to prohibit the same. They should also implement unversal health insurance schemes for their citizens. All these organizations working together can significantly reduce the magnitude of this problem and the impact it has on reducing the survival of children with cancer.

Apart from detention of their children in the hospital the parents also undergo a lot of other socio-economic,treatment-related and psychological experiences. The majority of them undergo financial difficulties and their income decreases. A big proportion of the parents who seek care at MTRH are casual labourers and hence any time they spend in the hospital taking care of their children means they lose their wages.This is a phenomenon that has been experienced in other countries like Indonesia as well. Challenges with transport including cost and time are the commonest reason why the patients missed appointments. This both is a result of the long distances from the hospital that most of the families live and the fact that the majority of them are from low socio-economic status.

The parents require more information and contact with doctors so that they are able to understand the illnesses of their children well. There are few doctors and parents feel that they use English and medical terminology which they do not understand leading to this situation. The

doctors are also considrered to be of a high economic status by the patients and this creates a divide between the two worsening the situation.The health-care providers acknowledged themselves that they do use difficult language when discussing issues withfamilies which point at poor communication skills.They also recognize that poor communication with parents will have a negative impact on adherence and survival which has also been demonstrated in Indonesia.The parents received a lot of information and support from the other parensts in the ward.Almost 90% of them felt they would not have understood their childs' illness without the information they got from the fellow parents.They were able to understand each other better.

Health-care providers agreed that proper protocal adherence impoves outcomes, although health-care providers believe most reasons for non adherence are not within their control. They alos believe that the more prosperous families are more likely to adhere and complete the treatment.They spend more time and give more detailed explanations to the rich family although they do not have a higher degree of empathy for them.This may mean that the more attention the prosperous patients get is based mainly on the financial gains for the health-care providers.

Use of complementary and alternative medicine(CAM) is quite prevalent among the childhood cancer patients. Almost all parents(95%) use complementary medicine either before coming to MTRH or within the course of the treatment.The commonest forms of CAM used are spiritual help and traditional healers. Use of CAM is a prevalent practice among children with cancer wordwide. High use of CAM has been noted in diverse coiuntries including Germany, Netherlands, Turkey, Jordan and Indonesia.Despite the widespread use of CAM parents never discuss it with the doctors(71%). About half of the parents were also told not to use CAM by the health care poviders. This shows there is a big discoonect between what the doctors expect of the families and the actual practice. It would be helpful if the doctors became more open about CAM and discuss it with the families without prejudice.CAM also delays families from seeking care and affects the time to diagnosis and start of treatment significantly.

Delayed diagnosis and start of treatment also could affect the outcomes of children with cancer. At MTRH we found that the median total delay for all the pediatric oncology patients was 102 days. This is longer than what has been reported by many studies even from low-income countries. The median health-care system delay(87 days) was significantly longer than

the median patient delay(4days). This long health-care system delay is probably a manifestation of the many problems affecting the public health system in Kenya. Complex referral patterns, health-care workers with limited knowledge on childhood cancer and lack of diagnostic and treatment facilities all contribute to this long delay.These long delays may cause patients to finally start treatment with advanced disease leading to poor survival. Having health insurance and use of CAM affected the patient delay significantly with use of CAM affecting total delay as well.

Wilms' tumor is one of the malignancies that has shown a very marked increase in survival in the last few decades in the high-income countries. It is one of the childhood cancers that has good chances of cure without having a lot of expensive high technology facilities.At MTRH before the year 2007 the survival rate was only 29%. In the years 2010 to 2012 the survival had increased to 41%. This happened after a period of several changes in terms of treatment of these patients. The treatment protocol was standardized and there was improvement in the expertise of the personnel. Dedicated pediatric surgeons and pediatric oncology nurses were available in thelatter period. All parents were also encouraged to register with NHIF.

The survival in MTRH is still quite low when compared to the high-income countries which have survival of about 90%.More still needs to be done to reduce the mortality. The majority of patients present late with advanced disease and with subsequent high mortality. All patients who present with stage I to III suffered no deaths or relapsed disease.This would imply that if the patients presented early we would have survival rates close to what the developed countries have.

Treatment abandonment continues to be a problem although there have been some improvement. Between 2010 and 2012 the abandonment rate among the Wilms' tumor patients was 30% which is lower than the 42% reported before 2007. As indicated earlier there is need to continue focusing on strategies to reduce abandonment. Data from Kenya shows that the most common reasons for abandonment among Wilms' tumor patients were lack of understanding of the treatment plans and financial difficulties. Enhanced parental education would be one factor that could be improved with minimal resources.

Childhood cancer, as seen from the foregoing dicussion, faces a lot of challenges for the survival to improve.However, most of the issues are not unique to Kenya but have been reported in other low income

countries. In the background of most of the issues is the problem of corruption.

Corruption is the abuse of entrusted power for private gain. A huge number of low-income countries suffer a lot of corruption. More than 91% of African countries score less than 50% on the corruption index as per the corruption score index of 2013. This index ranges from 0(very corrupt) to 100(very clean).

Corruption reduces economic growth and development. It also hinders equal distribution of resources anong the citizens of a country. Health-care is an integral part of any government in the world. It would not escape the effects of corruption. Health care is actually more vulnerable to corruption because of the multiplicity of players involved. These are international financial institutions, donors, government officials, hospital administrators,health insurers, health care workers, suppliers patients and the general population. Corruption can and does occur at all these levels. The government officials may fail to remit all the money to the specific hospital it is allocated toand retain some for selfish gain.Government officials can collude with suppliers to supply sub-standard products in exchange for kickbacks. Health-care providersengage in absenteeism and also solicit bribes from patients in order to serve them. Some officials representing donor agencies collude with the local personnel to provide mediocre service or inflate costs of services.

Corrupt practices lead to poor services in government hospitals and this scares away those who may want to seek serrvices in these facilities leading to an under registration of chidhood cancer patients and delays in diagnosis. Unavailability of supplies due to corruption means that chemotherapy and other supplies miss from the hospital. Familes have to purchase them from private facilities which is a big burden to the majority who live below the poverty line.Absenteeism and lack of facilities delays diagnosis and treatment. All these factors contribute to poor survival.

All the players in the health sector need to act together if this scourge is to be minimised. High moral standards and sytems for checks and balances should be put in place at all the levels mentioned above.There should be a system for rewarding good actions and punishing those who engage in corrupt practices without favouritism.

CHAPTER 14
RECOMMENDATIONS

On the basis of the findings of our studies, we give the following recommendations for better survival of children with cancer in Kenya:

1. A proper registry for paediatric oncology patients who present to MTRH should be maintained. A simple Excel file filled in by the clerks of research assistants can serve the purpose.
2. All Kenyans should be obligated to join the NHIF. This can be implemented both during the time of registration of births, as well as during the timeof registering for national identity cards. Registration of births usually occurs soon after birth and now it is almost a mandatory requirement to have a bitrh certificate before joining school. Since school attendance rates in the elementary education classes is very high, this would ensure that the majority of children would have NHIF if it is made mandatory. For the child to haveNHIF it means the parents must register, thus ensuring the whole family is covered.All Kenyans are required by law to acquire a national identity cared once they are 18 years of age. The government could use this opportunity to enforce acquisition of health insurance.
3. Training on childhood cancers should be made mandatory in all medical training curricula.This will ehnance the knowledge of the health care workers on childhood cancer. This will enable them to suspect and diagnose childhood cancers more readily.This should be enforced through the Ministry of Health which supervises the institutions.
4. Continuous professional educaton on childhood cancer should be delivered to all cadres of staff working in pediatric facilities.This will enhace the level of knowledge and hence lead to earlier detection of those children with cancer.The staff working in the pediatric oncology unit should liase with the professional organizations and be the facilitators of the sessions.
5. Parental education programs on childhood cancer should be implemented immediately at the treatment centers. The clinicians and psychological counsellors should lead these efforts, though all the members of the cancer care multidisplinary team should participate as well. All the parents should be informed about the diagnosis of cancer by the oncologist or paediatrician immediately after the diagnosis has been confimed. They should spend time

and explain to the families what the diagnosis and treatment will entail. This should be a continous process throughout the treatment period.

6. Local as well as international foundations should be approached to help cater for some of the costs of the families like transport and cost of NHIF.
7. The government should put an end to hospital detention practices in hospitals. Those families who cannot pay their bills should have the government offset them, but they should be encouraged to register with NHIF so that they do not continue having the same problems.

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APPENDIX 2: CURRICULUM VITAE

I was born and brought up in in the Central part of Kenya and later attended medical school at Moi University in the Western part of Kenya. I graduated in the year 2000. Thereafter I did my internship and was a medical officer from the year 2002 to 2005. I did my internship and also worked as a medical officer at the Moi Teaching and Referral Hospital. I then joined Moi University to study for a Master of Medicine degree (Child Health and Pediatrics) and graduated in the year 2009.

After graduating I worked as a pediatrician and head of Pediatric Hemato-Oncology unit at the Moi Teaching and Referral Hospital as well as an Honorary Lecturer at Moi University. In February 2015 I joined Moi University as a Lecturer in the department of Child Health and Pediatrics. As I work with children with cancer I am driven by the desire to reduce the mortality of these children in low-income countries.

APPENDIX 3: WORDS OF GRATITUDE

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I give a lot of appreciation to Peter van de Ven for providing me with statistical support.

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Finally I thank God almighty, in a special way for enabling me to have the chance to do my PhD and take care of children with cancer.